

Mind the Gap – Children Whose Parents Have a Dual Diagnosis

Problematic substance abuse is the most common comorbid condition among people with a severe mental illness (Siegfried, 1998), and yet there are many gaps in dual diagnosis service provision, primarily associated with the separate mental health and substance abuse services, lack of knowledge of workers in the area, and a poor base of evidence for effective treatment approaches.

More recently however, another gap is emerging. In both health and child protection fields, there is a realisation that an increasing number of people with a dual diagnosis are parents, which has major implications for service delivery.

There has been little recognition of the complex needs of these families and their children. In fact, there is only recently emerging evidence in the separate mental health and drug and alcohol fields to indicate an awareness of children whose parents have either of these disorders, let alone both.

The National Illicit Drug Strategy - Dual Diagnosis Project aims to address this gap in service delivery, and has been developed to better equip families, carers and service providers to support children of parents with a dual diagnosis. As part of the project, a review of the literature has been undertaken, and some of the findings from that review are presented in this report.

The literature is basically lacking in regard to children whose parents have a dual diagnosis - this is a clear gap in research and in service provision. Therefore, most of the observations in this presentation are drawn from the separate literature surrounding either substance misuse or mental illness.

For people who have a dual diagnosis, access to services is complicated – for those who are also parents, access to services is almost impossible. Most mental health and substance abuse treatment settings are designed for the adult individual, and in the limited dual diagnosis literature, support programs for families generally target the parents of adolescents with dual diagnosis, and not families affected by parental dual diagnosis.

No service takes formal responsibility for primarily addressing the children's needs when a parent has a dual diagnosis, and rarely are parent-child or family facilities provided (Dawe, Harnett, Staiger & Dadds, 2000). There is also a shortage of residential treatment services that will accommodate women (or parents) and their children, and in NSW this shortage has been noted by service providers (NADA, 2004). This may further delay women seeking help from fear of removal or separation of their children (Parity, 1998, in Lindsay & McDermott, 2000). In fact, a study of women in substance abuse treatment programs, demonstrated most had a history of treatment failures. A common reason for not completing substance abuse treatment was child-care issues (Killeen & Brady, 2000).

Drug Use, Mental Illness and Parenting

Like many at risk groups, the impacts of parental dual diagnosis can be overwhelming, and much of the literature is deficit focused, as opposed to identifying the protective factors and positive outcomes that do occur. In saying this, it is important to note, that not all mentally ill or substance abusing parents are inconsistent or ineffective at parenting – and not all children of these parents are impaired at a young age.

However, both parental substance abuse and parental mental illness can place children at biological, psychological and environmental risk. While it is difficult to draw conclusions from the literature, we can start to join a few dots, as a beginning to the complex picture that is parental dual diagnosis. What we are fast realising is that more research is needed in relation to the experiences and needs of children whose parents are affected by dual diagnosis.

We know that illicit drug-using women are less likely to access pre- and postnatal care (Finnegan and Kandall, 1992; Glover Reed, 1987, in Byrne et al., 2000). Similarly, women with psychotic disorders are more likely to receive less than optimal antenatal care (Miller, 1990, in Barkla, et al., 2000). In addition, substance abusing parents often avoid seeking help for parent-child problems for many reasons, including: the perception that nothing is wrong, lack of interest or lack of insight, isolation or marginalisation from traditional health services, and general disempowerment (Dawe, Harnett, Staiger & Dadds, 2000). Parents with a mental illness also have poor access of health and support services, due to factors including limited insight into the impact of the illness, poor social resources, fear and poor self-esteem and self-confidence in relation to parenting (Byrne et al., 2000). They may also avoid or delay hospitalisation to prevent separation from children or placement of children in care, thereby increasing the risk of exposing children to traumatic experiences and inadequate care (Gaining Ground Project, 1998).

Substance abusing parents often fear that they will be “found out” – that their substance use will be exposed, which may lead to intervention by child protection authorities (Finnegan & Kandall, 1992; Waldby, 1988, in Byrne et al., 2000), and parents with a mental illness often fear that asking for help regarding their children will result in a loss of custody (Hearle et al., 1999).

Affected families have complex needs, linked to issues such as poverty (Killeen & Brady, 2000), marital discord and marriage breakdown, poor housing and unemployment (Anthony, 1970; Cohen, 1993; 1984, in Byrne et al., 2000). Families affected by substance misuse often experience conflict, emotional or physical violence, decreased family cohesion and disorganisation, disrupted family rituals, isolation, and frequent relocation (Johnson and Leff, 1999). Children in families where a parent has a mental illness may also experience disruption to home and school, isolation from peers and other adults, and unmet developmental needs (Byrne et al., 2000). There may be a lack of extended family to provide support (Johnson & Leff, 1999), and an inability to seek support due to pressure to keep the illness hidden, and fear of being removed (Gaining Ground Project, 1998).

Children often experience a “lack of parenting” (Johnson and Leff, 1999) and may grieve for the loss of a ‘normal’ family (Worsham et al., 1997, in Orel et al., 2003). In the mental health literature, a phenomenon known as “parentification” has been described, whereby a child will take on unrealistic role expectations including care of the ill parent and/or siblings, and household management (Byrne et al., 2000). Children may also have difficulty in school, including: lower academic functioning, frequent school absence or lateness, are poorly clothed and fed, and receive less help from parents with school work (Kumpfer and de-Marsh, 1986, in Johnson & Leff, 1999). They may also have competing demands with additional responsibilities in the home environment. In some circumstances, children affected by parental mental illness have been observed as the “overachievers”.

The situation of substance abusing parents, has been referred to as the “competing demands of substance use and child rearing” (Campbell, 1997). Many substances have a sedating effect on the users, resulting in their inability to respond to their child’s needs appropriately (Hindman, 1977 in Besinger et al., 1999). Alcohol and other drugs also have disinhibiting effects leading to poor impulse control, low frustration tolerance or tendencies towards violence (Flanzer, 1993; Gelles, 1993; Curtis, 1986; Cicchetti & Olsen, 1990, in Tomison, 1996a), including physical or sexual violence (Araji & Finkelhor, 1986, in Tomison, 1996a), and domestic violence. Parental cognitive functions such as memory and consciousness may be affected by substance misuse, and many different adults may be caring for the children (Schuler, Nair & Black, 2002), thus impacting on the capacity of parents to provide safety, consistency and familiar routines

Children whose parents have substance abuse problems are also at greater risk of exposure to traumatic experiences, including witnessing drug use and intoxication, overdose or withdrawal, exposure to the drug culture and possibly illegal activities. When a parent has a mental illness, they may witness their parents often disturbing symptoms and behaviours, self-harm, poor emotional regulation and the impact of their parent’s hospitalisation (Handley et al., 2001)

For children of parents with a mental illness, other issues identified include: a lack of knowledge or understanding about their parent’s mental illness, and concern about future mental illness themselves (Byrne et al., 2000).

Outcomes

The literature indicates that children of parents with a dual diagnosis are at heightened risk of mental health problems.

Studies have shown that 25 – 50% of children with a mentally ill parent will also experience some psychological disorder during childhood, adolescence or adulthood, and 10 – 14% will be diagnosed with a psychotic illness at some point in their lives (Farell, et al., 1999).

Children of substance abusing parents show higher rates of behavioural and emotional problems, in particular oppositional, defiant and non-compliant behaviour (Smith, 1993; Willens et al., 1995, in Dawe et al., 2000), and they are at greater risk of substance abuse themselves (Johnson & Leff, 1999) and juvenile delinquency (Loeber, 1990; Ferguson & Lynskey, 1998, in Dawe et al., 2000).

Issues for Child Protection

It is also acknowledged that children may be at greater risk of child abuse or neglect. A history of mental illness or substance abuse has been associated with an increased risk of abuse and neglect of children (Browne & Stevenson, 1983). In addition, research indicates an increased risk of neglect and abuse by mothers who are highly stressed (Ethier et al., 1995; Abidin & Bruner, 1995; Mash, Johnston & Kovitz, 1983, in Harmer, Sanderson & Mertin, 1999), a common experience of parents with mental illness or substance abuse problems.

Data is limited however, studies indicate that the rate of custody loss for mothers with a mental illness is high (Miller & Finnerty, 1996, in Handley et al., 2001).

There are also high rates of undiagnosed psychiatric disorder among families known to child protection services (Zuravin, 1988, in Royal College of Psychiatrists, 2002).

Children of drug abusers make up the largest group of children entering the child welfare system (Barth, 1994 in Besinger et al., 1999). It has been estimated that at least half, and even up to 80 % of all parents whose children are known to the welfare system in the US, have substance abuse problems (Dore, Doris & Wright, 1995; Besinger et al., 1999; Barth, 1994, in Tomison, 1996a).

In NSW, the 1994-95 National Child Maltreatment Statistics indicated that 22 % of all substantiated emotional abuse cases were reported to result from a parent's substance abuse problem (Angus and Hall, 1996, in Tomison, 1996a). In Victorian protective services, 41.5 % of families sampled had substance abuse concerns recorded as contributing to child protection concerns. In cases of neglect, 57% of cases had a substance abuse concern recorded (Tomison, 1996a).

Resilience, Risk and Protective Factors

Despite the risks, not all children of mentally ill parents experience poor outcomes. Similarly, there are subgroups of children of substance abusers, who enjoy good health from birth; experience a positive home environment; and develop into socialised, competent and self-confident individuals (Johnson & Leff, 1999).

Protective factors include: having a responsive and safe home environment, supportive and highly organised family, and positive family qualities (Johnson et al., 1990, in Dawe et al., 2000; Richter & Bammer, 2001); the child's temperament and age at time of

parental breakdown (Garmezy et al., 1984); and, the extent and quality of the external support system, including the availability of one or more adults with whom the child can develop a supportive relationship (Feldman et al., 1987, in Cowling, 1996).

Early detection and intervention of parent-child problems is a major factor in prevention and treatment (Dawe, Harnett, Staiger & Dadds, 2000). Emerging evidence reveals that interventions are most effective at an early age, reducing as children move into adolescence (Dishion & Patterson, 1992).

Integrating Service Delivery

The present data showing the connections between substance abuse, mental illness and parenting problems, clearly suggest that dually diagnosed parents are in need of integrated treatment models that link substance abuse treatment to mental health and family support interventions (Zweben, 1996, in Hans, Bernstein & Henson, 1999).

Services should be comprehensive but flexible, to meet the individual needs of families when parents are unwell, while giving them the opportunity to be effective parents at other times (Cowling, McGorry & Hay, 1995).

Family education should be available - to ensure early detection and management of the two interacting illnesses and impacts; to develop specific individualised coping skills (Silverman, 1989), and to facilitate early identification of signs or symptoms in children at risk (Silverman, 1989).

Several authors support the availability of bibliotherapy (ie. age appropriate literature) about the nature of parental disorder, coping skills and details of supports available, in order to facilitate understanding of the issues (Wang & Goldschmidt, 1996).

Australian forums have provided recommendations for integrated, system-wide dual diagnosis training for service providers (Having it Both Ways, 1998). Education and training on substance misuse and addictive behaviours in the mental health workforce can enhance positive attitudes and increase confidence and skills in identifying and working with substance abusers (Gafoor and Rassool, 1998). Workers require access to knowledge about the effects and culture of drug and alcohol use (Campbell, 1997), and having realistic expectations about change and recovery also helps reduce staff burnout and frustration (Sciacca, 1991).

Few services have protocols and procedures to supporting individuals and families whose support needs cut across multiple service systems, in particular with those experiencing mental illness and substance abuse (Farrow, 2002).

Often, the links between alcohol and drug services and mental health services are informal and developed via individual worker relationships rather than at an organisational level. The value of more formalised links and protocols has been

recognised – in particular in relation to joint assessment, care planning and worker roles and responsibilities (Mellor, 1998).

Interagency collaboration is vital because of the complex health and social needs of dually diagnosed patients and their children. No one agency can undertake all parts of the child protection – drug and alcohol - mental health interface, and a holistic approach must be adopted to address what are often multi-problem, disadvantaged families.

The NIDS Dual Diagnosis Project

Aim:

To better equip families, carers and service providers to care for and support children of parents with a dual diagnosis.

Project Objectives

The Dual Diagnosis Project is informed by a promotion, prevention and early intervention approach with a focus on collaboration between services, education and resource development. It is designed to:

- provide guidelines for DoCS workers to identify and appropriately refer parents experiencing co-existing mental health and substance abuse problems;
- encourage collaboration between child protection, mental health and drug and alcohol service providers, including non-government service providers, in meeting the needs of children who have a parent with a dual diagnosis;
- improve the understanding of family members and out-of-home carers on the impacts of dual diagnosis on children in their care; and
- ameliorate long term harm to children by providing family members and out of home carers with practical guidance and age appropriate resources on dual diagnosis to engage and educate the children in their care.

Project Partners

The Dual Diagnosis Project is managed by the Department of Community Services in collaboration with the Mental Health Co-ordinating Council (MHCC).

Project development will be in consultation with an advisory group comprised of representatives from relevant government and non-government agencies including: DoCS, MHCC, Network of Alcohol and other Drug Agencies (NADA), Family Support Services Association (FSSA), as well as other relevant drug and alcohol services, mental health services, multicultural and indigenous groups. A local reference group of key stakeholders will be consulted throughout the project.

Project Scope

The project is of a 15-month duration, and will initially involve:

- i. Identification of existing models of practice, resources and training strategies;
- ii. Identification of information and support needs of children, families and carers related to dual diagnosis;
- iii. Identification of service gaps and needs, and models of service provision, and
- iv. Identification of information and training needs strategies to assist DoCS frontline staff and NGO's.

The project has two major streams:

1. The development of a resource package:
 - (i) a training package designed to educate DoCS workers and other support workers caring for children and families where a parent has a dual diagnosis;
 - (ii) practice guidelines and referral protocols designed to assist workers to better care for and support children and families where a parent has a dual diagnosis; and
 - (iii) a package of age specific information resources to assist families and out of home carers to understand the issues faced by children of parents with a dual diagnosis and provide carers with a set of tools to assist them to better care for affected children.
2. Implementation, education and support
 - (i) consultation on complex cases involving children, families and carers when a parent has a dual diagnosis, by NSW Department of Community Services' caseworkers including case planning;
 - (ii) development of appropriate networks, attendance at interagency forums and liaison with relevant agencies including DoCS' Community Service Centres, mental health services, drug and alcohol services and NGO support organisations (eg. family support services) to build collaborative working partnerships and to promote the delivery of seamless service provision on dual diagnosis issues within the DoCS Metropolitan West;
 - (iii) assisting in the recruitment and training of specialist carers in order to locate appropriate placements for children of parents with a dual diagnosis;
 - (iv) co-ordinating training needs for casework teams and individuals within teams; and
 - (v) dissemination of practice guidelines to internal and external stakeholders.

Conclusion

The term “mind the gap” was cited in the UK child protection literature, as an expression used by senior managers to staff about interface working. It seems that this is most relevant in dual diagnosis practice. While there is little evidence surrounding the specific needs of children whose parents have a dual diagnosis, the literature from the mental health and substance abuse fields provides a beginning awareness of issues, needs and service approaches.

The lack of empirical research in these fields, makes it difficult to draw any conclusions. However, we can recognise the need to address these gaps. Programs and strategies, such as resource development and co-ordination of care across systems, must be developed in consultation with the stakeholders, including the families, carers and service providers, and be evaluated to determine efficacy and outcomes.

Much remains to be done, and many service systems are yet to identify and address the issue of parental dual diagnosis. It is hoped that service development strategies and education such as the NIDS Dual Diagnosis Project can begin to improve the capacity of service providers, and the systems they are part of, to identify and address the needs of families affected by parental dual diagnosis, and thereby improve outcomes for children and young people.