

## **Children and Adolescents with Pervasive Developmental Disorders: The Role of a Crisis Service**

*Susan D. Sweet*

### **Abstract**

*This paper discusses the role that a crisis service may play in serving children and adolescents with pervasive developmental disorders. At Youthdale Treatment Centres, we operate a 10-bed, inpatient, emergency secure treatment unit under the Child and Family Service Act. Although few are referred, children and adolescents with autistic spectrum disorders may be admitted to this unit provided they meet the mandatory admission criteria. The families who decide to seek out this kind of service, the circumstances precipitating the admission, our role in serving these families, and the profound impact these patients have on our staff and unit are discussed.*

### **Youthdale Treatment Centres**

Since 1989, the government of Ontario has regulated admissions to Youthdale Treatment Centres' secure, 10-bed, in-patient unit (Acute Support Unit) as "emergency admissions to secure treatment" under the Child and Family Services Act. The unit's mandate is to serve adolescents aged 12 years to their 16th birthday (although children under 12 years may be accepted with the consent of the Minister) for a maximum period of 30 days. This unit admits children and adolescents with pervasive developmental disorders, as long as the mandatory admission criteria under the Child and Family Services Act (Part VI - Extraordinary Measures, Chapter 11, Section/Article 124) are met. These criteria require that patients have a mental disorder and that, as a result, they have caused, attempted to cause, or by words or conduct made a substantial threat to cause, serious bodily harm to themselves or other persons. The program is also charged with preventing patients from causing or attempting to cause further harm and with providing appropriate treatment. Finally, there must be no restrictive method of appropriate treatment (it should be a voluntary in-patient or outpatient service). Each year we admit a small number of patients with pervasive developmental disorders, who are characterized by severe and pervasive

difficulties in social interaction and communication, and by the presence of repetitive, restricted, and stereotyped activities, interests, and behaviours (see DSM-IV, 1994). A review of consecutive admissions to the unit over the 18-month period from April, 1999 to October, 2000, indicated that 10 of the 294 patients (3.4%) had been diagnosed with a pervasive developmental disorder. These patients included 8 males and 2 females, with a mean age of admission around the onset of puberty ( $M = 13.4$  years,  $SD = 1.5$  years, range 11.0 to 15.6 years). Half of these patients (5 males) were relatively higher functioning and had done fairly well until adolescence, at which point behavioural problems developed and they were identified as having Asperger's Disorder, which is characterized by difficulties with social interaction and repetitive, restricted, and stereotyped activities, interests, and behaviours, but with no accompanying delays in language development, cognitive development, or non-social adaptive skills (see DSM-IV, 1994). Most of these children were diagnosed within the year prior to their admission (2 children) or during their admission (2 children). The remaining child was identified 3 years prior to his admission. The other half of these patients (3 males and 2 females) were relatively lower functioning and were most often diagnosed with Autism, which has all the features of a pervasive developmental disorder listed above (see DSM-IV, 1994). Most of these children were identified much earlier in life (3 with Autistic Disorder and 1 with Rett's Disorder), although 1 child had been diagnosed with a developmental delay and was unable to access services for children with Autistic Disorder until diagnosed during the admission. Providing an accurate diagnosis and/or confirming previously made diagnoses are often important tasks for our psychiatric staff. The number of children with pervasive developmental disorders we are asked to serve is usually small as Youthdale is not an ideal setting for these patients. Our programs are not generally designed for them and often they are unable to take advantage of therapeutic opportunities (e.g., peer group therapy). Further, as part of their disorder these children have great difficulty with transitions (see DSM-IV, 1994). Most parents are keenly aware of the distress an admission will cause, and they do not want to put their child through such upheaval for a short-term placement.

### **Circumstances precipitating admission**

The families who reached us seem to have had several things in common. Most (8 out of 10) had maintained their children in the home until the admission with little in-home support. As their children entered puberty they became increasingly difficult to manage, usually due to a pattern of ongoing violence which escalated at that time. In all 10 cases there had been physical aggression/attacks toward others, and in 7 the aggression had escalated, and the family had been less able to cope since the onset of puberty. In addition, the outbursts were noted to be explosive and unpredictable in 6 out of 10 cases. Further, the nature of the attacks was generally quite serious, and in 4 cases, of such intensity that the police had to be called to intervene. Half of the children admitted had threatened another person with a knife, and 2 had stabbed

another person. Four of the 5 children with Asperger's Disorder had made verbal threats to kill a family member. Thus, family members had suffered a variety of injuries, ranging from cuts and bruises to injuries requiring surgery. One family slept with their bedroom doors locked to prevent assaults throughout the night. In addition to harming others, 9 of the 10 children admitted also had histories of harming themselves (e.g., head banging, slapping themselves, hair pulling) and suicidal threats were made by 2 children with Asperger's Disorder. There was also frequent damage to the home and 4 families reported significant property damage. Despite their difficult situations, we have seen great concern on the part of parents for the welfare and happiness of their children, guilt and distress about the admission, and a high level of involvement with their children while on the unit.

### **Onset of puberty**

Puberty seems to be a particularly difficult time for the children we see at Youthdale. While the onset of puberty can be related to major gains in some individuals, others experience marked deterioration of their behaviour and skills and overall developmental losses (American Academy of Child and Adolescent Psychiatry, 1999; Bauer, 1995; Kobayashi, Murata, & Yoshinaga, 1992) and it is this second group that we tend to serve. Prevalence rates of deterioration at puberty have been reported to be as high as one-third to one-half (Gillberg & Schaumann, 1981; Gillberg & Steffenburg, 1987). Some children who experience developmental losses do eventually stabilize, although often not to the level achieved prior to puberty (e.g., Gillberg & Schaumann, 1981). Gillberg and Steffenburg (1987) found that one-fifth of the children in their study did not stabilize and continued to deteriorate over time.

Regarding the children with Asperger's Disorder, the deterioration of their behaviour may be related to the onset of puberty, which is associated with an increasing awareness that they are different from and ostracized by their peers. Studies have indicated that, in contrast to individuals with Autistic Disorder, those with Asperger's Disorder may have a greater "theory of mind" and that related skills may develop later than usual (Bowler, 1992), perhaps placing the maturation of these skills during adolescence. Individuals with pervasive developmental disorders may also be affected by the initial appearance of comorbid conditions during adolescence, such as depression (American Academy of Child and Adolescent Psychiatry, 1999; Gillberg, 1985). Social factors and traumatic events have been linked to deterioration of behaviour and skills during adolescence (Gillberg, 1985; Kobayashi, Murata, & Yoshinaga, 1992), as has the development of seizure activity (Gillberg & Steffenburg, 1987). However, in many cases there is no identifiable cause for the increased difficulty at puberty.

### **Family stress**

The families we see have reached the point where they are willing to accept any help available, even though it might not be what they had originally envisioned. They are exhausted and increasingly unable to cope with the escalating behaviour of their children, especially given that their resources are already depleted by the heavy day-to-day demands of parenting their children. Prior to admission, half of the children required constant supervision and help with self-care, and 4 had significant difficulties sleeping which required parents to be awake throughout the night. Families were also worn down by their search for services and attempts to advocate for their children. Many of them developed a growing sense of hopelessness around improvement and the availability of accessible services. In fact, 3 parents reported significant difficulty with depression and/or anxiety. Studies of respite care have found that families who made use of such services had more difficult children with lower functional levels than those of non-users, and that the parents were pessimistic about their situation (Factor, Perry, & Freeman, 1990).

When families were able to locate other services, they were usually on an outpatient basis and unable to decrease the risk of harm posed by their children significantly. More often (6 out of 10 cases), families repeatedly tried to access services only to be faced with a variety of obstacles (e.g., long waiting lists for the limited resources available, difficulty finding and employing in-home workers, emergency rooms that could provide medication but not admissions). The only intervention that seemed readily available to many families was medication, and often many medications had been tried prior to the admission ( $M = 6.7$ ,  $SD = 4.1$ , range 2 to 15 medications). However, families had found that medication did not reduce the risk of harm, leaving them to continue seeking treatment options. A medication review was often requested during the admission in order to help sort out the various medications in use.

### **Placement decisions**

During the admission, many families had to face the difficult issue of whether or not the home was the best place for their child and the situation sufficiently healthy and safe for the family in general. Prior to the admission, some parents had gradually come to the realization that they might no longer be able to meet their child's needs. Other parents were simply seeking a break from the struggle they had been going through and had not considered a change in placement. Sometimes the admission raised questions for these families because the contrast between what their life had been like and what it subsequently became during the admission was so stark, and because they heard professionals voice the same concerns they had been having. They were then faced with returning to the previous situation with few supports or moving the child out of the home, which seemed a lose-lose situation to most families. We have found one of our primary roles to be supporting families in making this difficult

decision. With support, 5 out of our 10 families decided to place their children outside the home on a long-term basis following their discharge from Youthdale. These families often needed help coping with the resulting stress, guilt, and sadness. Families also needed help searching for placement alternatives. As a condition of admission to Youthdale Treatment Centres, each child must have a community-based case manager who, together with our staff, will help search for the services necessary upon discharge. However, in many cases there is no placement immediately available and families may need assistance in making interim arrangements. An equal number of our families decided to have their children return home following discharge, despite recommendations for residential placements in 3 cases. Families in this situation should feel that the door has been left open to them to return for additional help and to reconsider their options at a later time if they feel it necessary. Indeed, one family did return for services shortly after the initial discharge and their child was subsequently placed in residential care. Whatever parents decide, they should be given support and their expertise regarding the needs of their child and family respected.

#### **Effects on staff and the unit**

A discussion of our experience with children who have pervasive developmental disorders would not be complete without noting the effect of their presence on our staff and the unit. Although these children form a very small percentage of our patients, they have a profound impact on both our front line and professional staff who, not unlike parents and families, require support while providing these children with care. Staff find it quite demanding to work with these children, especially those with severe Autistic Disorder who usually require one-to-one staffing 24 hours a day. We frequently seek funding for additional staff during these admissions, both to provide the children with more support and to ease the strain on the rest of the unit. Staff find many aspects of working with these children challenging (e.g., creating individual programming given the constraints posed by the nature of the unit, finding some means of communication, determining what a child enjoys or finds aversive on the unit, easing transitions given that staff shifts and patients frequently change). Struggling to adequately address these special needs has created in our staff a great empathy for the families involved and a recognition that the situation must be far more stressful for parents, who cannot seek relief from other staff or go home at the end of the day.

Previous information suggested that there were problems with children with Asperger's Disorder. This paragraph suggests otherwise. Unfortunately, staff have also learned first-hand about the aggression families face and, despite a high staff-to-patient ratio, incidents of aggression occurred on the unit. These incidents were mainly limited to the children with Autistic Disorder<sup>1</sup>. The children with Asperger's Disorder tended to stabilize and to do relatively well within the structure and

predictability offered by the program. Among these children there were few incident reports in general ( $M = 4.8$ ,  $SD = 5.0$ , range 1 to 13 reports) and only 2 incidents of aggression towards staff and 3 incidents of self-harm occurred. In comparison, the children with Autistic Disorder tended to go through an initial brief "honeymoon period." Their behaviour then deteriorated, serious safety issues arose, and a great number of incident reports occurred ( $M = 21.0$ ,  $SD = 12.2$ , range 3 to 37 reports), including 41 reports of staff injury (e.g., hair pulled out, bites, cuts on faces, kicks to the head) and 22 incidents of self-harm. At times the aggression affected the functioning of the entire unit (e.g., patients became distracted and concerned when they heard screaming or moaning, and they became fearful when they witnessed physical attacks on staff). Another serious challenge for staff was dealing with inappropriate sexual behaviour. The sexual behaviour of children and adolescents with pervasive developmental disorders has not been researched in much detail, although it can be a great concern for caregivers. Among the children with Asperger's Disorder there were no incidents of this nature while within the structure of the unit, although concerns were noted in the histories of 2 patients prior to admission. One child had reportedly tried to get things he wanted by threatening to make allegations of sexual abuse against his group home staff, which was obviously very concerning to our staff. Among the patients with Autistic Disorder, there were 16 incidents of inappropriate sexual behaviour (e.g., touching other patients, removing their clothing, grabbing female staff's breasts). These incidents caused considerable stress for staff, who are very aware of the need for appropriate boundaries and safety on the unit.

## Conclusions

Effectively managing patients with pervasive developmental disorders continues to be a learning process for us, and we have gained much through our limited experience with this population. As noted, we have learned that relatively higher functioning children with Asperger's Disorder do fairly well within the structure and predictability of the unit. Their behaviour often stabilizes and they are able to experience success in the program. In contrast, relatively lower functioning children with Autistic Disorder generally do not do well in our program and a shorter length of stay is often desirable, as their behaviour tends to deteriorate over time. Although unclear why this occurs, it is likely related to the difficulty the children have with the many changes in staff in the unit, their frustration related to the difficulty of clearly communicating their needs and wants to staff, and the lack of activities and intervention opportunities specifically tailored to their unique needs and developmental levels. Therefore, working closely with families and others involved in a child's care to gain a detailed history and understanding of each child prior to the admission is essential in order to make the milieu as comfortable as possible and to best prepare everyone involved to work successfully with these very challenging young people. In the future, the development of preventative services to minimize the number of children who will need to make use of crisis services is essential. Services

promoting early identification and providing early intervention to children could help to decrease the need for later crisis intervention. Recently, a move has been made in this direction by the provincial government of Ontario (Ministry of Community and Social Service), which has funded early intensive behavioural intervention programs across the province. It will be some time, however, before the long-term impact of these programs upon children as they approach adolescence can be measured. In the meantime, additional funding and initiatives to support children as they approach adolescence are imperative in order to provide them and their families with service options that meet their individual needs.

In conclusion, a crisis service has an important role to play in serving children and adolescents with pervasive developmental disorders. Our contributions to their care vary depending upon the individual needs of each child and family. We can provide an accurate diagnosis for those children who have gone unidentified or have been misidentified prior to their admission. We can carry out a thorough medication review to help determine the efficacy of the various medications in use, and suggest the addition of new ones or make other changes as needed. In many cases we are able to stabilize the behaviour of the children admitted and decrease the risk of harm to themselves and other people, although this occurs more often with children who have Asperger's Disorder versus those with Autistic Disorder. Finally, our key role in serving these families most often involves providing them with support in making very difficult decisions about whether or not they are able to continue caring for their children within the home.

### Endnotes

- <sup>1</sup> This group includes the child who was diagnosed with Rett's Disorder, as her behavioural difficulties were consistent with those of the children who were diagnosed with Autistic Disorder.

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