Community Participation in an Admission Process to a Government-Operated Facility for Children and Adolescents with Severe Autistic Disorders

Patti Reed

Abstract

This paper describes the experience of a middle manager in admitting children and adolescents with severe autistic disorders to a government-operated residential facility. Success of the admission process is attributed to an open, collaborative process involving community members and Ministry employees. It underscores the value of the inclusive, participatory process in making difficult decisions and for using tools to keep the process of decision making objective and accountable.

In my experience in working within several different community organizations, once eligibility for a service or services is determined and a person is accepted onto the waitlist, the decision about who will be admitted to receive services is traditionally an internal decision made by staff. There may or may not be board representation on an admissions committee, but more often than not the decision is made in the best judgment of staff based on various criteria such as funding, current resources, complement with clients already receiving services, needs and so on.

Typically, decisions made about the use of resources and who will receive services within a government setting are made by internal staff, and whatever final approvals are required must be signed off by the Minister or his/her delegate in senior administration.

This paper addresses the demonstrated success of an open, collaborative admission process that involved community members in conjunction with Ministry employees in a government operated facility to make the final recommendations for decisions.

The Process for Admission to Long Term Care

TRE-ADD (Treatment Research and Education for Autism and Developmental Disorders) is one of four independent programs run by Thistletown Regional Centre, a children's facility funded directly by the Ministry of Community and Social Services (now the Ministry of Community, Family and Children's Services, MCFCS). Since the 1970's, TRE-ADD has offered a tertiary level service for children and adolescents with severe autism or pervasive developmental disorder. It serves the geographic catchment area of Toronto, York Region and Peel Region. Treatment services include: Section 19 classrooms at both elementary and secondary level (on and off site); ten residential beds in two group homes (until recently); research in best treatment practices; and, Family Support Services (FSS) which include case coordination, counselling, support groups, parent relief and case management for children who live in the community. The clinical team includes a consulting psychiatrist, psychologists, nursing staff, recreation staff and a consulting speech and language pathologist.

It is the FSS team that is responsible for accepting intake referrals, ensuring that proper documentation and consents are completed, and managing the waitlist for all programs in TRE-ADD. *Notice that I did not say admission to services.* Typically, decisions about *who gets admitted* have been made internally within the specific service area by the management and staff team involved.

As everyone knows, there are few to no residential beds for children, particularly children and adolescents with severe behavioural problems. Due to a lot of community pressure, MCSS announced funding to open *five* new residential beds at Thistletown Regional Centre in the TRE-ADD program in February, 2000. (Thistletown Regional Centre already had a vacant house on-site.) There had not been a new resident admitted (or anyone discharged) from the program for almost 10 years! Therefore, there was very little experience or vested interest in any particular admission process, so TRE-ADD developed a new process that made every effort to be transparent, fair, objective, and collaborative, in order to serve those most in need of a highly intensive, highly structured and restrictive environment such as TRE-ADD.

First level screening

The Ministry's public announcement to open a new five-bed child and adolescent home for children with severe autistic disorders was made in February, 2000. We decided that agencies and families might not have made recent referrals for residential services since there had been so little movement for so long. Therefore, we opened up the referral process until the end of March, 2000, and all referrals were considered equally, no matter how long they had been on the list. The referrals

consisted of:

- Males: 23; Females: 10
- Age 5 (youngest referral) - 10 = 7
- Age 11 - 15 = 13
- Age 16 - 17 = 10
- Over 17 = 3

Once the list was "closed", the FSS Team members reviewed the residential waitlist (33 applicants) to screen for eligibility based on the following criteria:

- Child must have a DSM-IV diagnosis of autism or pervasive developmental disorder
- Child (and/or family if child is currently placed) must currently reside within the catchment area of Thistletown
- Child must have date of birth between 1983 to 1995 (may be in the17th year)
- Family must be interested in immediate placement

Families were contacted to confirm interest. Some families choose to be on the waitlist "just in case" for future placement. Some families had been on the waitlist for so long their child was now an adult. By mid-April the list was verified and finalized at 26 actively waiting families.

Second level screening

In their case coordination/case management role, the FSS Team often knew the families waiting for services. Each FSS worker reviewed clinical records and historical documentation to screen for eligibility based on the following criteria:

- TRE-ADD's group home is deemed the least restrictive environment to meet the child/adolescent's needs
- Children and adolescents must be able to benefit from the existing group composition

The following questions were asked:

- What other less restrictive living environments have been pursued (and documented)?
- Does the child/adolescent have the ability to function in the community with appropriate supports in place? (ensure this is treatment issue, not a resource issue)
- Has child accessed parent relief and/or out-of-home placement in the past?

- What community agencies/services are currently involved with the child and his/her family?
- Has the child/adolescent been identified as a priority by the local "hard-to-serve process"? (Toronto Hard to Serve Committee, Peel Exceptional Review Committee, York Region Community Pressures List, MCSS Advocacy office)
- If a child has a current residential placement, is it at imminent risk of breaking down? If so, why?

This turned out to be a very difficult process for staff because they were used to advocating within the program for the needs of the families they represented. This process forced them to identify only those families who had exhausted all other community supports and to identify children who were currently exhibiting very difficult to manage behaviours. Even though the child (or adolescent) may be completely appropriate for our services, TRE-ADD offers a *tertiary* level service for those children that have had unsuccessful experiences with community supports in their past. Often, the children referred would be on the local "hard-to-serve" list. The FSS workers were familiar with the family situations and realized that it was probable there would be residential placement issues in the future but that the family was coping at this time; they would then have to eliminate them from the residential waitlist for this admission process.

The second level screening was completed by the end of April, 2000 and reduced the eligible referral list to 15 candidates (for 5 beds).

Third level screening

It was at the third level that outside community involvement was introduced. An *Assessment Tool* was developed which described the adolescent's skills and abilities through interviews with parents, teachers and community agency professionals and observations of the child/adolescent at home and/or school. In order to promote unbiased and objective reporting, the *Assessment Team* was comprised of the FSS worker (TRE-ADD), a residential manager from TRE-ADD, and the referring agent (community case manager/advocate or Children's Aid Society (CAS) worker). All three members visited the child's home, current living situation (if not at home) and school (if attending). The Assessment Team jointly completed one report in which they reached consensus on the content. They were asked to make recommendations for placement based on their observations.

All visits, interviews and Assessments (including recommendations) for fifteen children/adolescents were completed by May 24, 2000. There were a total of eleven children (from the original list of 35) that reached the fourth level of screening.

Sample Profiles

I don't like to describe a child without discussing their strengths and skills first and foremost, but the following two profiles only capture the residential history that these two adolescents presented and a little about why evaluation of each of their situations was so difficult. The names have been changed to protect confidentiality.

Case 1

Erin lived at home with her parents until September, 1999, and attended a local segregated school. Throughout 1998 and 1999 her behaviour changed dramatically. She began pinching, hitting, kicking and biting others as well as crying and screaming and throwing furniture for no apparent reason. Her parents had to lock her into her room to ensure her own safety and that of themselves and other family members. In September, 1999, she was admitted to a Youthdale emergency crisis bed for two weeks, then discharged to a temporary respite bed in the Toronto Association for Community Living (TACL) (October, 1999 to March, 2000). She was hospitalized in an adult psychiatric ward from March 19, 2000, to April 3, 2000, due to aggressive behaviours. While in hospital she was in a four point mechanical restraint at all times with a 1:1 paid staff person (funded through CAS). She lost her independent toileting skills at this time.

Erin was then discharged to a 30-day emergency bed at the J.D. Griffin Centre in April, 2000, with 2:1 staffing by day (funded by CAS) and still remained there with no discharge plan during this admission review.

The parents remained very involved with their daughter and visited her almost daily wherever she was living.

Case 2

In 1994 John was described as self-abusive (banging his head several times each day), non-compliant, tantruming, biting, kicking, pinching, scratching his parents and other children and throwing furniture. He had limited communication and very poor self-help or life skills. The family was able to get case management support from TACL and funding for Special Services at Home. In January, 1995, John was enrolled in school one hour/day, five days per week and one parent had to remain with him in the classroom to help manage his behaviours. In April, 1995, the family continued to have a difficult time and the CAS became involved in looking for out-of-home placement. CAS funded 24 hour staffing support in the family home while they were searching for a residential placement.

From November, 1995 to April, 1997, John lived in a children's group home funded by CAS but was discharged due to safety concerns for the other children living in the

home. He was moved to another privately operated group home in April, 1997, until October, 1999. Again, he was discharged because he was running into the street and aggressing against other children and staff. John moved to a temporary respite bed provided by TACL from October to December, 1999, located in a separate apartment with 1:1 staffing and no other children to ensure the safety of himself and the other children. He then went to one of the 30-day safe beds (operated by Griffin Community Support Network) from December to January, 2000 and moved to another temporary emergency placement from January to June, 2000, again living with 1:1 staffing 24 hours per day funded by CAS.

John's parents have always remained incredibly committed and throughout all of his living situations in the past five years he has gone home every weekend to visit his family.

Fourth level screening

A *Residential Admission Committee* was struck to review all submitted applicants (based on the Assessment and Evaluation reports). Committee members included:

- Director of TRE-ADD (Chair of Committee)
- TRE-ADD Manager of School-based Services
- TRE-ADD Consulting Psychiatrist
- TRE-ADD Nurse
- TRE-ADD Psychologist
- TRE-ADD Consulting Psychologist
- Parent with a pre-school child diagnosed with autism (Peel)
- Parent with a child attending Section 19 classroom (Toronto)
- Parent with an adult child who had "graduated" from TRE-ADD (Peel)
- Professional representative from York Behaviour Management Services (York Region)
- Professional representative from Griffin Centre Children's Services (Toronto)

The criteria for selection of parent members was to recruit parents familiar with TRE-ADD and its services and without interest in residential placement for their own family members. Parents were recruited who had committee experience as well as the ability to be "broad thinkers" and consider the needs of the program and the children as a whole.

The criteria for selection of agency members was to recruit senior managers who had experience with children with autism/PDD and/or experience in a children's residential placement setting.

Each report was circulated to committee members in advance of an all day selection meeting. All identifying information (including name and geographic area of origin) was removed. Each member was asked to review the reports and prepare questions and highlight comments for discussion at the presentation of the profiles. Each FSS Worker was given 15 minutes to present the information contained in the Assessment and Evaluation document. This was also the opportunity for committee members to ask questions for clarification, based on the written information they had received. FSS Workers were asked not to "plead their case". They were asked to remain factual and as objective as possible.

A *Ranking Tool* was developed which included a scoring system. All individual scores were aggregated at the end of each presentation although they were not shared until all presentations were completed.

Once all of the presentations were completed and the scoring complete, an all member discussion was structured to further elaborate on individual client situations within the context of all 11 children. This was a more subjective opportunity to ensure that scoring on the ranking tool in the morning remained consistent with the scoring in the afternoon. As it turned out, the children selected through the individually completed ranking tool with the highest scores directly correlated with the children considered most in need for immediate placement through the group discussion.

The Residential Admission Selection Committee forwarded their recommendations through the Director to the Administrator of Thistletown Regional Centre for Ministry approval.

The Ministry considered this entire process to be inclusive, objective and fair utilizing the best clinical judgment for the most appropriate kids and accepted the recommendations exactly as forwarded.

The final five children included one adolescent from York Region, one adolescent from Peel Region, and three adolescents from Toronto. All five children had been involved with the Child Advocacy Office and identified as high need children. All five were also identified on their local "Hard-to-Serve" Committee lists as children most in need.

Admission

It was determined by the TRE-ADD senior management team in February, 2000, when the MCSS announcement was made that it would be clinically detrimental to clients and unreasonable for staff to have all new residents and new staff move into a brand new group home. Therefore, while the above process was happening in the spring, decisions were also made to shift the existing 10 residents and current staffing

complement across three houses and admit new clients into each of the three homes. Once house renovations were completed, primary workers had lengthy discussions about which clients should live together based on their current strengths and needs. Remember, people had been together within the two houses for many years!

Once those moves were planned, primary workers were asked if they were willing to "follow their client" and remain working with them. Every person volunteered to do this!

Once the parents had agreed that their child could be admitted to TRE-ADD, a staff meeting was held with all senior staff in the residential program. Profiles were presented similar to the Committee presentations but in more specific detail with the name, present living situation, present school situation and family involvement of each child.

Each residential staff member was asked to develop a rationale for choosing which child was most suitable for which of the three homes. They were asked to consider such things as:

- Sleeping habits (overnight demands)
- Eating habits
- Level of restrictiveness (behaviour demands)
- Physical care demands
- Day programming need
- Family involvement
- Compatibility with other residents in the home
- Discharge planning

A meeting was held mid-June to discuss the individual rationale for specific groupings. Once it was finalized which house each adolescent would move into, a primary Instructor Therapist was assigned and transition plans were made for visits, meeting the parents, arranging overnights, etc. New residents started moving in mid-July (with staggered admission dates) and everyone had moved in by mid-August, 2000.

Summary and Feedback

We had a review meeting with the TRE-ADD management team and the members of the Residential Admissions Committee to debrief about the decision-making process.

The general consensus was that the process was a very good one in helping to make very difficult decisions. The most rewarding part was that the adolescents deemed most needy through assessment, evaluation and ranking were the ones that were

ultimately chosen to be admitted. The process was considered fair in that more than one person completed the assessment (including outside the agency) and several people did the ranking.

Future Considerations

We need to refine both the assessment and the ranking tool. A pre-meeting of the committee to fully understand consistent use of the ranking tool is suggested for the future. Additionally, standardized assessments are suggested with the inclusion of formal diagnostic scores. Feedback from the parents on the Committee was very positive. They felt that they were full participants in the process and that the tools were helpful in keeping them objective while also giving the opportunity in the full group discussion for more subjective comments. In my opinion, families who were *not* admitted were more accepting of the decision because they were aware of the open process that was being administered and realized that other families had more demanding needs at this time.

In summary, I strongly encourage everyone to consider a more inclusive process for decision-making in your admission processes. The use of tools that you develop helps to keep the process more objective and is more accountable to your clients, your agency, your colleagues and your funders.