Kerry's Place marks anniversary with renewed mission

By Brock Weir

Kerry O'Neil's parents knew they had a mission when their young daughter was first diagnosed with autism, but the first question they had to tackle was an all-important ?How??

That answer came when they teamed up with other families travelling the same journey to establish a home for kids living on the autism spectrum at a farmhouse near Collingwood.

That was nearly a half-century ago.

The landscape has changed significantly in the intervening decades, but one thing has been a constant in the organization that still bears Kerry's name: the dedication of Kerry's Place Autism Services to help individuals and families living on the spectrum live better, healthier lives.

Kerry, accompanied by her sisters Kay and Dawn, was on hand last week to mark the milestone 45th anniversary of Kerry's Place Autism Services, which now serves more than 250 families across Ontario.

While Kay said she and her family were honoured to take part in the 45th anniversary of the organization, it was a bittersweet anniversary in the sense that when the O'Neils and other founding families laid the groundwork for the organization, they were hoping ?there would be a cure long before this.?

?So much work was done during the first 10 years of development of this organization to make the foundation for what Kerry's Place is today,? said Kay. ?It was a lot of hard work and so much credit goes to the staff that worked with the students. They knew nothing about what to expect from persons with autism [but] they stuck with it, learned a lot about children with autism, loved their job, loved the children, and they did a lot of work.

?The first 10 years provided an enormous learning experience for all: staff, students, parents, medical professionals, educators, government agencies and members of the community. The students taught many people to become more tolerant, more understanding and more understanding of persons with disabilities because at that time everybody was told [to put impacted children] in institutions.?

A lot can happen in the space of a decade.

Beginning in 2000, Kerry's Place began putting an increased emphasis on the ?clinical? component of what they did. Since then, they have become very well-known for the clinical support they provide their clients, a level many organizations don't have.

?We still envision a future where all persons with autism are participating fully in their communities,? said Dr. Sue Vandevele-Coke, President and CEO of Kerry's Place. ?Our mission is to enhance the quality of life for those individuals and for their families through evidence-based supportive practice. That remains today. We have about 250 people we support. We have lots of community supports, which includes respite, camps, so from growing from a small group of four or five homes, we now have eighty homes and apartments in which we support individuals.?

While those values are holding firm, the landscape surrounding autism and its treatment here in Ontario is not. In the last few months, the Province's approach to autism treatment has changed rapidly, leaving many families angry and uncertain. Kerry's Place, however, is rolling with the punches and these changes on the Provincial front are reflected in their new Strategic Plan.

The Ontario Autism Program, said Dr. Vandevele-Coke, is ?in chaos? but ?we're ready for the new program, which we know will be evidence-based and probably based on the choice of the parents, and it will probably be fee for service.?

?That means we will change from a provider, which gets funding by the Ministry, to a fee-for-service model,? she said. ?We have developed a model where we have costed out all of our supports that we would provide and we're ready. We just need the clients from the waiting list. I want to assure you that even though it seems like it is chaos out there, we're inviting parents who want to join our program. Whatever happens, we'll be ready.?

Kerry's Place is also putting increased emphasis on helping a group they have watched grow over the last few years who seem to get ?forgotten? in the larger picture; that is, individuals between the ages of 18 and 30.

?They are not getting any funding, they have never gotten much funding either from grants, and we're reaching out to that group [and] providing them with employment counselling, with teaching, communication skills, increase in social skills, and these programs for people who are seeking employment, we have had some great success. Through our funding, through fundraising, we're keeping this program and we're hoping we can demonstrate positive outcomes for the program and people get jobs, are able to secure jobs, and eventually we hope we can get government funding. In the meantime, we will continue to raise money and continue to build this program.?

Then, there are older adults,
including those founding teens like Kerry, who are now over the age of 60.

?We have to plan for the
future,? said Dr. Vandevele-Coke. ?We're observing, many of our individuals are having chronic health problems just like everyone else when they turn 50 to 60 years old. We're looking at what can we do to help those individuals? We started with funding an end of life program, where as people who are in that age category, we're meeting with families and we're talking about what will happen if a catastrophic event happens. What are your plans? What do you want to do? I know that sounds difficult to talk about death and to talk about chronic disease, but that's the reality and we have to plan for it. That's what we're doing. We're having an end of life program that we're putting into place. In addition to that, we're hiring a nurse practitioner who will be responsible for a group of individuals who have extensive health care problems and they can be a liaison with physicians and they can have a plan for what are the needs of the individuals.?