

When Living with Your Parent is No Longer Enough

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Sometimes, in spite of our wishes, parents face a complex reality that lead them to make one of the toughest decisions they will ever make. I share with you my account of having to place my son in a group home.

A little background:

My son M. has needed a lot of support from a very young age. He was born with a cardiac malformation for which he underwent surgery the day after he was born. He developed epilepsy at six months of age. Delays in his development were evident around one year of age and he received a diagnosis of autism when he was three and a half. It goes without saying that M. required ongoing medical follow up. M. began showing aggression from two and a half years of age, in large part due to the fact that he could not communicate his needs and the seizures he experienced (many per week).

From a very young age, M. received services from many agencies, Surrey Place Centre, Geneva Centre for Autism, Holland Bloorview Kids Rehabilitation Hospital and a variety of disciplines, occupational therapy, speech and language, physiotherapy, specialists in behaviour and Applied Behaviour Analysis (ABA). He was also one of the first children to receive Intensive Behavioural Intervention (IBI).

It was evident very early that M. required a specialised classroom to meet his many complex needs. He was in the same special education class from junior kindergarten to grade 6. Aggressive behaviour increased significantly in grade seven and this class could no longer meet his needs. At this point, we made the decision to change schools. M. transferred to a specialised class in a treatment centre, which was not only a change of

schools but of language as well, from French to English. M. is still at that centre and will be until age twenty-one.

Moving to a group home:

By fifteen and a half years of age, M's aggressive behavior became increasingly difficult to manage, in spite of all the support he received at school. Discussions were focused on whether M. could remain a student at the school. I was asked to connect with a local agency to explore additional support at the school. Eventually we (parents) were encouraged to consider placement in a group home and advised to explore the process involved. My first reaction, as M's mother, was total refusal. I explained that M's father and I had no intention of entertaining that option until M. was twenty-one. We were then strongly encouraged to start the process immediately given that it is a very long process and spaces are very limited, even more so in adulthood. Reluctantly and with heavy hearts, we started the process all the while telling ourselves it would take years and the situation could possibly get better. I communicated with the Special Needs Team at Delisle Youth Services, Toronto, where the social worker began compiling the file. All the while, many serious incidents occurred which put my safety at great risk. This sped up the acceptance of our case. Within six months, a placement was offered in our own city. This is unusually fast! As a mother, the idea of my son leaving our home and having to admit that the situation was not only complex but potentially dangerous tore a hole in my heart. After visiting the group home and many meetings with the director, we accepted the placement. M. was only sixteen when he moved out. Without a doubt, this would be a very

difficult move but with a good transition plan and lots of communication, M. coped with this change well.

Important to know:

Documentation is key to preparing a case for placement. It is imperative to keep all reports and communications about services received from the beginning, in chronological order. The social worker will need all this information when compiling a file.

It is normal to resist the idea being presented because, as parents, we hope to be able to care for our children ourselves and for as long as possible. For me, it was not natural that a child be raised by someone other than his/her parents and in a setting other than the family home.

The guilt is very intense and this is normal. As I put paper to pen to share my experience more than three years later, I still feel the guilt. I have adjusted to the situation but there remains a constant tug on my heart strings, in particular on Sunday night when I drive him to the group home.

Children in residence remain our children! Decision making power remains yours. You are involved at all steps along the way. It is important to stress this from the beginning. I continue to go to all specialist appointments, school meetings, etc. I get calls on a regular basis asking my opinion about various matters. No decision is made without our approval. It is up to you to remain involved in your child's life.

No one knows your child more than you! It is important to share the strategies you use with your child, strategies related to how to calm him or her, their nutrition, sleep habits, sensory needs, etc. What really helped was the "How To" guide I created, full of details and strategies related to all aspects of M's life.

Become an intricate member of the transition plan. It is essential to speak for your child. Explain the pace and frequency you envision for the visits to the group home. You know your child, what they can handle and how long it may take to adjust to a new environment. Take the necessary time.

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In our situation, M. comes home every weekend. We pick him up on Friday evening and bring him back on Sunday night. He spends holidays, school holidays and many weeks in the summer with his parents.

Some highlights:

- M. has made great gains in terms of his independence.
- He eats a greater variety of food, due to eating with others at the residence. Nice influence!
- His behaviour has improved significantly, in particular tolerance related to transitions and changes.
- He has the opportunity to socialize and learn to live in the community through the many activities organized for the residents.
- M. receives constant supervision, even a night (due to his epilepsy), which is something I could not offer him. This allows me to "recharge my batteries", have more energy for the weekends and appreciate our time together.

Having a whole team care for my son during the week has helped to significantly reduce my level of stress. I go to work without the dread of waiting for the urgent calls at all times of the day. My quality of life has improved and I am able to pursue some of my own interests.

When M. turns twenty-one, is no longer at school and facing a very limited number of day programs, he will be able to remain in the residence during the day while waiting for a spot in a program able to meet his particular needs. Without this support, I have no idea what we would do without access to programs.

In Conclusion:

In spite of the very difficult moments we lived throughout this process, today I am confident that we made the right decision.