

THE CANADIAN JOURNAL OF AUTISM EQUITY
LA REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

VOLUME 4 | ISSUE 1 | APRIL 2024

Autistic Children and Group Homes: A Personal Testimony

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RECOMMENDED CITATION: Bedard, S. (2024). Autistic Children and Group Homes: A Personal Testimony. *The Canadian Journal of Autism Equity*, 4(1), 18–22.



Autistic Children and Group Homes: A Personal Testimony

Les enfants autistes et les foyers de groupe : Un témoignage personnel

Stephen Bedard

Abstract

There is no guaranteed outcome for an autistic person when it comes to housing. It can range from complete independent living to living with family to being placed in a group home. In this personal account, the story of one family with two autistic children with high needs is shared. Placing a child in a group home is difficult for any parent. The emotional cost is great enough but there are additional challenges that can add to the pain of the situation.

What is shared is not meant to generalize to the experience of all autistic people, not even all autistic people who are placed in group homes. This account is a snapshot of one family's experience that may highlight some of the problems with the system and potentially point to areas for improvement.

Resumé

Il n'y a pas de résultat garanti pour une personne autiste en matière de logement. Il peut s'agir d'une vie totalement indépendante, d'une vie en famille ou d'un placement dans un foyer de groupe. Dans ce récit personnel, l'histoire d'une famille ayant deux enfants autistes qui ont des besoins importants est partagée. Placer un enfant dans un foyer est difficile pour n'importe quel parent. Le coût émotionnel est déjà assez important, mais il y a d'autres défis qui peuvent ajouter à la douleur de la situation. Ce qui est partagé n'a pas pour but de généraliser l'expérience de toutes les personnes autistes, ni même de toutes les personnes autistes qui sont placées dans des foyers de groupe. Ce récit est un instantané de l'expérience d'une famille qui peut mettre en lumière certains problèmes du système et qui indique éventuellement des domaines à améliorer.

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Keywords

Autism Spectrum, group Homes, housing Policy, parenting

Mots-clés

Spectre de l'autisme, foyers de groupe, politique du logement, être parent

Introduction

When parents have children, there is a moment when possible, futures flash before their eyes. This includes everything from teaching them to drive to what major they will choose in university to where they might raise their own families. Part of this includes the experience of how long children will live at home.

Ideally, parents are not longing to become “empty nesters” the day their first child is born, but there is at least an unspoken expectation of what things will be like. Many parents assume the child will remain in their home for the teen years and then move away from home either to begin postsecondary education or when they begin working. There are not too many variations on this theme.

But what happens when autism enters the picture?

Autism exists on a spectrum, meaning some people may require different levels of individualized support ranging from minimal to significant. As a result, outcomes relating to education, careers, and housing can vary widely. Some autistic people may be comparable to or slightly later than their peers in moving out, while others may never be able to move away from their parents. There is no single autistic experience when it comes to decisions about moving away from parents.

What I intend to do in this essay is to describe what our experience has been with two of our autistic children finding sustainable housing. This is not a statement about what all parents can expect, although based on anecdotal evidence, our experience is not unique.

To provide a balance to what will be shared below, the two autistic children I focus on are only half the autistic members of our family. I was diagnosed when I was in my forties. While I was a quirky child with some strongly held interests, I hit many of the milestones of my peers, although often a few years after them. I moved out of my parent’s house in my late twenties and was married in my early thirties. Our youngest daughter was diagnosed with autism in her teens and continues to live with us. While she will likely require some support when she moves out, we do not anticipate a housing solution comparable to our two oldest children.

A Diagnosis Arrives

When our two oldest children were diagnosed with autism, we did not know what to expect, including future living arrangements. At first, we hoped that they would be mildly affected by autism and that after some therapy they would have a life typical of others their age. This would include post-secondary education, moving out, finding a career, and starting a family.

It was not long before we discovered that they were significantly impacted by autism and that they would not experience some of the milestones of their peers. We then began to prepare ourselves to be long-term caregivers. Long after our younger children would move out, we expected our older autistic children would still be with us. We eventually found out that our second assumption was as incorrect as the first.

I have written elsewhere on the emotional cost of sending our children to live in group homes. (Bedard, 2023) Rather than focusing on how we were able to reconcile this decision with our role as parents, I will focus on the process of placing our children in group homes and the challenges that we faced.

Our Daughter's Story

Our daughter, who was seven at the time, was a wonderful little girl but her behaviours were difficult to manage. She would destroy our possessions, damage the interior of our house, and most seriously, would injure our younger children. This is not necessarily typical of autistic people. Of our immediate family of seven people, four have been diagnosed with autism and our oldest daughter was the only family member who was aggressive. We tried numerous interventions, including sending her for residential treatment to get her medications regulated, but nothing worked. Life in our house became more and more difficult.

We met with a group representing many of the agencies that worked with disabled children to express the crisis that our family was facing. They listened intently to our concerns and agreed that something needed to happen. Unfortunately, they had nothing to offer. They explained that there were no beds available and that even if there were, there was no funding to pay for that bed. They had nothing to offer us but advice.

The chairperson of that group told us that there was only one option if we truly believed that our ability to care for our daughter at home was at an end. We were advised to call Family and Child Services and inform them that we were abandoning our daughter. While I know people who have been forced to take that option, we were not prepared to go that way yet.

Remarkably, an hour after that meeting, we received a phone call from that chairperson telling us that both a bed and the funding had become available and that our daughter could move into a group home early the next week. It was what we had hoped for, although not without an emotional cost. On one hand, our daily routine became much easier but on the other, we struggled with feelings of abandoning our daughter. Even the newfound calmness of our home made us feel guilty. It is something that we are still coming to terms with.

Moving our daughter into the building was not the end of our challenges. The group home was a school that had been renovated into dorms. None of the other residents had the traditional diagnoses that are considered a disability, and they were mostly children that had been taken in by Family and Children's Services. Caring for a child with autism resulted in a steep learning curve for the staff.

Less than a year after our daughter's placement, we were informed that the government was reluctant to continue the funding. The cost of keeping a child in a group home with all that entails is significant and it will always be economically beneficial for the government if the child is raised at home with the parents. It required many phone calls and much advocacy on our part to confirm that our daughter could not return home and that the funding was justified.

Once the funding was settled, there was more change. The large institutional settings had fallen out of favour and the school building was closed. Thankfully, the agency still owned a house in which they could keep four residents, including our daughter. They also chose to focus on children with intellectual disabilities rather than the population they had previously cared for. It ended up being a good fit for the most part and the agency was willing to work with us.

Ultimately, this decision, as painful as it was, improved our relationship with our daughter significantly. We were able to focus on just enjoying our visits with her instead of being weighed down by the challenges of her behaviour. She seemed to save up all her best behaviour for her

visits with us. She also enjoyed her new home so much that she would insist on going back after a day even if we had planned a weekend visit. We are thankful that we were able to make this housing arrangement.

Our Son's Story

We knew that our daughter had high support needs, and while we did not expect her to move from our home at such a young age, we knew it would happen eventually. The housing outcome for our son was much more uncertain. While at a similar end of the spectrum, our son was less a danger to others and more to himself. Our son had the tendency to run away, and being nonverbal and lacking basic safety awareness, this was a problem. We literally would pile up boxes in front of the front door so that he would not leave the house during the night.

At around the age of thirteen, his behaviours began to shift toward harming other family members. While not as consistent in his aggressions as our daughter, the lack of predictability made things difficult. He was also at that age when his body was growing rapidly, and he could harm even an adult if he tried. We looked into having him placed in a group home and once again were pointed to Family and Children's Services.

While abandoning our son was offered as an option, as we had previously encountered with our daughter, we were thankfully given other options. We did not have to surrender all our parental rights. It was suggested that we enter into a temporary care agreement in which Family and Children's Services would take custody of our son, while we retained our parental rights. This would provide a respite and having him in their system would open doors for longer-term care.

This option was attractive but not without concerns. There were some within the agency who wanted to discourage us from seeking a placement. One worker, who was involved in the intake, informed us that they were not prepared to offer the assurance of safety that we required given his elopement risk. The worker explicitly stated that if we continued the process of seeking a placement, that we were putting our son's life in jeopardy. Looking to have our son move into a group home was already making us question our parenting ability; this was taking it to the next level.

Since the situation at home had developed to the point that we knew a placement would be necessary, we went ahead and entered into a temporary care agreement and our son was placed in a house with several other boys. We soon found out that the worker's warnings about our son's safety were not idle.

We received a phone call mid-morning from the group home, telling us that our son had been missing for approximately 1.5 hours. Despite knowing that there was a flight risk for our son, they left him alone outside to wait for the school bus. By the time the bus arrived, our son was gone. We arrived at the group home to find many police cars, a K-9 unit, and a media truck. Over the next hour, we were convinced that our son had died, especially as the group home was in a high-traffic area and he had demonstrated no safety skills. We eventually discovered that our son had walked almost 10 km to his school in the next city, having memorized the route from the bus rides, and assuming that the bus was not coming for him. His abilities in terms of memorization and safety skills far surpassed our assumptions.

Our son was later placed in a home with a different agency and things have become much better. He has outgrown the need to elope and settled into a comfortable routine. He enjoys visits with us and is treated very well by the staff that work with him.

The Problem is Bigger

While we faced many challenges along the journey of having our children placed in group homes, we are one of the fortunate families. Both our children were eventually moved into a group home that was run by an agency that understood how to meet their needs. They were able to finish off their childhood living in the same house and enjoying each other's company. While they were originally placed because of challenging behaviours, they have both developed into wonderful young adults who are loved by their family and the staff at the homes. Once they reached adulthood, they moved to separate houses operated by the same agency. The people who work with our children take care of their needs and seek for them to have fulfilling lives. They still experience meltdowns and other difficult behaviours, although less frequently than in their childhood. We have had to come to terms with the fact that other people were better equipped to care for our children than us. Once we let go of what we considered the expected parental roles, we were able to transition into a new and healthier relationship with our children.

Sadly, this is not every family's story. We know of families who have had to take the step that we were spared from. They were forced to abandon their children and surrender all parental rights. Others have been able to keep their children into adulthood and by the time they become aggressive, there are few opportunities available for them to be placed. Even if the children do not get aggressive, and most do not, some parents find it difficult to care for adult autistic children and may feel that it is beyond their ability. The waiting lists for people to be placed in group homes can run into the decades. (Viau, 2019)

Conclusion

What has been described here is not the experience of everyone with autism. It was not my experience as an autistic person who moved away from my parents in my late twenties or of our other daughter, who is a teenager with autism and who still lives with us. But this is the experience of some families with autism.

There are some significant needs when it comes to housing autistic people, children, and adults, who require a group home setting. There is a need for more group homes, large enough to house up to four residents. There is a need for a simpler and more accessible process for disability funding. There is a need for better trained staff, who not only will keep residents safe but will also help autistic people to live their best lives. Each of these areas have their own sets of challenges and we hope that sharing our story will help influence movement in the right direction.

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