

## INFORMATION SHEET 6

### ASHTON'S PLACE

As parents we all have something in common. It is best described by Katy Elphinstone in her book *Bridging the divide. Childhood from the autistic perspective, and how we can do it better!*

#### *Dos and Don'ts*

"What do we have in common as parents and carers of autistic children? Well, probably concern and worry for a start, about how they might do or might get along 'out there'. Certainly the feeling of loving your child so much you'd probably go to the world's end and back, if it would help them to be okay. A deep wish to support them in finding their own way in life, in achieving inner equilibrium and resilience, and in becoming self-confident – and the strong desire that through these things the chance will be gained for their gifts to shine through and be appreciated fully, both by themselves and others."

### OUR PERSONAL JOURNEY BEGINS: ASHTON'S PLACE IS CONCEIVED

We had two beautiful twins in 2014, Ashton and Anastasia. We were thrilled and looked forward as every parent does to marking their achievements and supporting and encouraging them as they moved into their future.

Our lives took a turn in the road as six months later, one of our twins was not keeping up with developmental milestones. One of our twins was in a different place in this world. It took us 18 months to get a diagnosis. Many visits to doctors and specialists to confirm what we knew. Ashton was officially diagnosed at two with an autism spectrum disorder.

Our son was diagnosed in 2016. We found too many unanswered questions. A lack of funding. And a lack of research with practical implications for children with ASD.

It took 12 months to be able to begin the official diagnosis process and it took six months to receive the confirmed diagnosis. Then the options began. "*Early intervention is the key*", were the words we heard over and over again. Research indicated Ashton needed 15-25 hours of early intervention each week for it to be effective.

*(N.B. "Intervention" is now referred to as "support" as identified in the National Guideline for Supporting the Learning, Participation, and Wellbeing of Autistic Children and their Families in Australia, "Supporting Autistic Children Guidelines, December 2022".)*

Where to begin? Yes, there was help in setting us in the right direction, but then what? We wanted more; more information! More answers!

Your child may need a variety of therapies, for example, speech therapy, occupational therapy, and psychologists. This all takes time and money. Our aim is to help families with the financial burden they face through an ASD diagnosis. *Ashton's Place* will enable this burden to be lifted so parents and caregivers are better able to concentrate all their efforts on their child.

In 2016, it was suggested that Ashton needed 15-25 hours of early intervention per week. From an early intervention perspective, I felt it took too long to officially diagnose our son. Too much time was lost and I was not a professional in this area so I didn't know what to do. I couldn't find enough information for a child under two with Autism. Programmes that I did find here and in America only deal with children older. What were we to do?

We had to join him in his place and we had to figure out how to make it have a sense of peace for him. This has led us on the biggest learning curve of our lives. We have learnt a great deal, and from this experience has come a clear understanding for a need to have a charitable foundation, which we called [Ashton's Place](#).

Our hearts are heavy when we think of the struggles for the families in the ASD community. Our journey has given us an increasing awareness of these struggles and the impediments faced by families who are anxious to provide for their children with effective educational and therapeutic therapy, but whose efforts are being thwarted by confusion regarding best practice and financial restraints. My husband and I are compelled to do something that will give these children a chance to find their place in this world.

*Ashton's Place* was founded because of these reasons: it is a foundation that will help support these families and offer funding for further research, which is needed. It requires a combined effort and needs government, community, and business involvement at all levels to achieve the below goals.

## OUR GOALS

**GOAL 1** Ensure our son was on the best pathway he could be. He needed to find his place in this world;

**GOAL 2** Set up a charitable foundation that could help all families choose a pathway of intervention that suited them and their child without the financial burden and stress.

### GOAL 2 ACHIEVED:

Ashton's Place is established November 2018;

Ashton's Place is funding families with the high costs of Early Intervention Programmes for their children.

**GOAL 3** Set up an Early Intervention (*from 2022, now known as "supports"*) Programme with proven positive outcomes in an Early Childhood Centre that would be the first of many that would cater to and support autistic children and their families.

### GOAL 3 ACHIEVED:

Autism Connect Early (ACE) Programme is born 14th July 2019;

Ashton's Place announces a partnership with the University of New England;

Our aim is to offer a model of early intervention (supports) that meets the needs of the child and their family. Our ACE Programme will provide much needed early intervention (supports) utilising proven early intervention models and will allow research to be conducted on an ongoing basis to evaluate and develop a programme that is relevant and one that will serve children and their families into the future.

**GOAL 4** Ensure there were funds available for research into this disorder, labeled as ASD (Autism Spectrum Disorder).

The latest figures from 2018 suggest that the autism prevalence rate is up by an estimated 40 per cent to one in 70 people. Autism Spectrum Australia (Aspect) has revised its autism prevalence rates from one in 100 to an estimated one in 70 people in Australia on the autism spectrum. That is an estimated 40 per cent increase or around 353,880 people.

If that many children are diagnosed with autism, why aren't there: 10 colleges; 100 childcare centres specialising in care for children on the spectrum; 100 school programs, and; 20 universities offering research into the practical implication for early intervention programmes that produce positive outcomes? Where are all of these children; are they forgotten because of a lack of funding or lack of a cohesive plan?

At the time of diagnosis, we had only two programmes that offered intensive early intervention to choose from.

I believe the answers to my questions do lie in a lack of funding and knowledge from sources that matter and can make a difference. It is the only reasoning I can come up with to my questions of why. If the programmes that exist now are successful, why are there not more of them?

Why do families have to struggle every day with autism without the necessary help they need? Surely, it is not because we have governments that do not realise the importance of the early years?

There is enough research out there for government that if we get it right early, we will place less of a financial burden on society in future years. There are too many gaps and there are too many obstacles for parents and families. We must help parents overcome these obstacles and give them the support they need to assist them in their day-to-day lives.

*(UPDATE: in 2024, parents are still waiting up to six months for NDIS to approve funds).*

Ashton's Place will help ease the financial burden that these families face. It can cost up to two thousand dollars a week to give a child on the spectrum the supports that "are likely to lead to the most meaningful and sustained increase in the child's learning, participation, and wellbeing." *CRC Guidelines 2022, p86.*

What will happen next with your child is daunting for parents of children on the spectrum. When our son was diagnosed three years ago in 2016 (he is now five), we were given no list of where to go or who to contact or what websites or organisations might help. We got a speech therapist and psychologist's number and we had to manoeuvre our way through the world of autism. We want to make that easier so parents have a pathway to follow.

***Our path lead us to the inception of Ashton's Place and so our story began.  
We are well on our journey.***

*(UPDATED April 2024; the term "early intervention" was widely used up to 2022, the "Supporting Autistic Children Guidelines" were developed in December 2022, which refers to this as "supports").*

Ashton's Place will support families on this journey. Although much has been done, much more is required:

1. We need to ensure there is funding to establish pathways for education and training for educators and families to enable the best strategies and supports for children that are diagnosed on the spectrum;
2. We need childcare centres that have staff who are skilled in caring for children on the spectrum. This is so parents have a place to take their child where they know they will be cared for and will receive the attention their child deserves. This will allow the necessary supports to begin; and
3. We need to ensure the importance of the early years are recognised by governments, academics, researchers, and professionals dealing in this field.

***Imagine a world where you do not understand what it feels like to know the joy of a cuddle, the sense of connectedness through joint attention, the excitement of sharing with another human being by the simple gesture of a point. Not being able to communicate that you are hungry or thirsty, the pure joy of play... our autistic child had lost this awareness. We aim to give this back to him.***

For some it was there and was lost, for others we will open their world to the joy of play, of communicating of living a socially connected life. They will find their place in this world and be the best they can be.

We acknowledge our family and friends that help us in our daily support, along with the many professionals whom without their experience and knowledge Ashton would not be at peace in his place. He would have been lost in his own world, alone and unaware.



*Please note, these are my thoughts and lived experiences. It does not reflect all autistic children's parents or families or the autistic community.*

**SOURCES OF INSPIRATION:**

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