“Autism and drowning – the underreported issue” is the first report of its kind in Australia. Produced by Autism Swim, the report makes a valuable contribution to raising awareness on the risk factors associated with wandering occurrences and drowning for those with Autism Spectrum Disorder (ASD).

The report outlines the importance of addressing the issue, what is being done in Australia to reduce these risks, and what further action needs to take place. The statistics and insights contained in this report emphasise the often high-risk nature of those with ASD, especially around aquatic and other environments. This report aims to drive discussion about the problem, highlight what solutions are being achieved and what the future could look like.

The report provides a wealth of interesting information and advice for all members of the community, regardless of their connection to ASD. I applaud Autism Swim for taking the lead in highlighting this issue and providing important insight and resources to help address it.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>About Autism Swim</td>
<td>3</td>
</tr>
<tr>
<td>Background</td>
<td>8</td>
</tr>
<tr>
<td>Autism Swim Advisory Board</td>
<td>9</td>
</tr>
<tr>
<td>What is Autism Spectrum Disorder (ASD)?</td>
<td>10</td>
</tr>
<tr>
<td>Prevalence</td>
<td>12</td>
</tr>
<tr>
<td>Autism Spectrum Disorder (ASD) and Drowning</td>
<td>14</td>
</tr>
<tr>
<td>Addressing the Challenges</td>
<td>22</td>
</tr>
<tr>
<td>Resources</td>
<td>24</td>
</tr>
<tr>
<td>Testimonials</td>
<td>26</td>
</tr>
<tr>
<td>References</td>
<td>28</td>
</tr>
</tbody>
</table>
Founder, Erika Gleeson, is a Senior Behaviour and Skill Development Specialist in Autism Spectrum Disorder (ASD) and cognitive deficit. She is widely recognised as Australia’s leading expert in wandering and drowning prevention for those with ASD/cognitive deficit.
The priority of Autism Swim is to encourage and support inclusive aquatic services for those with ASD and other abilities, ultimately reducing the disproportionately high risk of drowning for those who have ASD.

As experts in the field, Autism Swim understands the risk factors associated with drowning and ASD, and focuses on developing resources and delivering educational services to address these risk factors.

A recent study undertaken by AMAZE Victoria indicates that while 98% of Australians have heard of ASD, only 4% of those with ASD (or their families) indicated that they felt people in the community know how to support those with ASD.¹

The aim is to promote inclusive practice, to build an educated and skilled community, and increase the opportunities available to this population group.
Families who have children with disabilities identify swimming as their most popular physical activity and overall favourite activity.²

Water activities such as visiting the beach or swimming in a pool play a significant role in Australia’s iconic culture. However, very little Australian research has been conducted into drowning and ASD. As a result, for this report, Autism Swim has referenced the latest evidence-based American statistics.

Suggested Citation:
Autism Swim, ‘Autism and drowning – the underreported issue’ 2019

Disclaimer:
While Autism Swim endeavours to provide reliable data and analysis and believes the material it presents is accurate, it will not be liable for any party acting on such information.

Contact:
Any enquiries about or comments on this publication should be directed to Autism Swim (hello@autismswim.com.au).

Autism Swim participant, Paddy
Autism Swim currently operates across six countries and seeks to further expand into global markets. Current markets include Australia, New Zealand, Malaysia, United Kingdom, Canada, and USA.
COMPANY MILESTONES

Autism Swim company timeline

2017
- **JULY**
  - International expansion.
- **JUNE**
  - Training becomes available online.
- **MAY**
  - Wandering and Drowning Toolkit is released. The only one of its kind.
- **JANUARY**
  - Inaugural Dippers event (Coogee, NSW) begins.

2016
- **AUGUST**
  - Autism Swim is established. Website is launched.

2015
- **FEBRUARY**
  - Research into drowning for those with ASD commences.

2018
- **JULY**
  - 200 instructors across 6 countries.
- **SEPTEMBER**
  - Announced as Anthill Smart100 award winner.
- **APRIL**
  - Advisory Board established.
- **MARCH - JULY**
  - Autism Swim is selected for Remarkable Accelerator Program (technology to enhance the lives of those with a disability).
BACKGROUND

Autism Swim is an international, social enterprise of experts specialising in wandering and drowning prevention for those with ASD and other abilities. Autism Swim is the first and only certifying body specific to ASD and aquatics.

Founded and established in Australia in 2016 by Clinical Director Erika Gleeson (G.C Autism, B.A Behavioural Science), Autism Swim takes a multi-disciplinary approach, combining the expertise of Autism Specialists, Behaviour Specialists, Occupational Therapists and Swimming Instructors to achieve the best possible outcomes for the individuals they support. Autism Swim operates under the skilled leadership of an Advisory Board.
AUTISM SWIM ADVISORY BOARD

Dr. Geoff Potter
Autism Specialist

Alexandra Scott
Policy Advisor

Chris Henshaw
Accountant

Audrey Variyan
Swimming Instructor and Parent

Cheryl Pettinau
PR and Communications Advisor

Kylie Jones
Events and Community Engagement
WHAT IS AUTISM SPECTRUM DISORDER (ASD)?

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition which impacts how someone views the world. People with ASD can experience difficulties with communication, social interaction and restricted/repetitive interests and behaviours.

These challenges are often accompanied by sensory issues such as an oversensitivity or undersensitivity to sounds, smells or touch.³
While people with ASD present with certain challenges, they of course also present with a vast array of abilities and strengths.

The term “spectrum” is used to emphasise that autism presents differently in every single person.

Many individuals with ASD present with Behaviours of Concern, one of which is wandering.

Over 50% of individuals with ASD have a propensity to wander.⁴

Further information can be found at page 17.
In Australia, statistics indicate that an estimated 1:70 people have ASD.⁸

It represents the highest population of approved plans within the National Disability Insurance Scheme.⁹

New research indicates that 1:40 children in USA have a (parent-reported) diagnosis of ASD.⁵ In 1995, the reported prevalence of ASD was 1:500.⁶ This represents a 1150% increase.

The Centers for Disease Control (CDC) report that autism is an urgent public health concern.⁷
Autism representation, of approved plans, in the Australian National Disability Insurance Scheme⁹

Table E.10 Active participants with approved plans per quarter by disability group - NATIONAL⁹

<table>
<thead>
<tr>
<th>DISABILITY</th>
<th>PRIOR QUARTERS</th>
<th>2017 - 18 Q4</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Autism</td>
<td>43,452</td>
<td>29%</td>
<td>6,856</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>42,493</td>
<td>29%</td>
<td>5,314</td>
</tr>
<tr>
<td>Psychological Disability</td>
<td>10,999</td>
<td>7%</td>
<td>2,483</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>7,796</td>
<td>5%</td>
<td>894</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>6,377</td>
<td>4%</td>
<td>1,663</td>
</tr>
<tr>
<td>Other Neurological</td>
<td>6,820</td>
<td>5%</td>
<td>1,208</td>
</tr>
<tr>
<td>Other Physical</td>
<td>5,799</td>
<td>4%</td>
<td>1,141</td>
</tr>
<tr>
<td>Acquired Brain Injury</td>
<td>4,911</td>
<td>3%</td>
<td>819</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>4,207</td>
<td>3%</td>
<td>1,212</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>3,687</td>
<td>2%</td>
<td>660</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>3,125</td>
<td>2%</td>
<td>447</td>
</tr>
<tr>
<td>Other Sensory/Speech</td>
<td>2,700</td>
<td>2%</td>
<td>217</td>
</tr>
<tr>
<td>Global Development Delay</td>
<td>1,806</td>
<td>1%</td>
<td>583</td>
</tr>
<tr>
<td>Stroke</td>
<td>1,825</td>
<td>1%</td>
<td>390</td>
</tr>
<tr>
<td>Spinal Cord Injury</td>
<td>1,851</td>
<td>1%</td>
<td>271</td>
</tr>
<tr>
<td>Other</td>
<td>280</td>
<td>0%</td>
<td>47</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>148,128</strong></td>
<td><strong>100%</strong></td>
<td><strong>24,205</strong></td>
</tr>
</tbody>
</table>
Drowning is the leading cause of death among children with ASD. According to US-based National Autism Association, between 2009 and 2011, drowning subsequent to wandering accounted for approximately 90% of total (US) deaths reported in children with ASD aged 14 and younger.¹⁰

Children with ASD are 160 TIMES more likely to die from drowning compared to other children.¹¹

Children 14 years and younger with ASD are 40 TIMES more likely to die from injury than the general paediatric population.¹¹
Wandering is the tendency for an individual to try to leave the safety of a responsible person's care or a safe area. This has the potential to result in harm or injury. It is often referred to as absconding, elopement or fleeing.

Nearly 50% of children with ASD attempt to escape from a safe environment.¹² This is nearly four times higher than children without autism.¹²

There are a number of reasons why someone with ASD may wander, including:

- To get away from something they may find aversive (such as sensory discomfort).
- Reach something of interest/head to a favourite or preferred place.
- Escape demands or anxieties.
- Curiosity.
- They are lost or confused.¹³
Wandering causes significant stress to parents and the community.¹² 58% of parents of children with ASD report wandering/elopement as the most stressful of ASD behaviours.¹² Research indicates that half of families with children who wander do not receive guidance from professionals.¹² More than one third of children with ASD who wander, are unable to communicate their name, address, or phone number.¹²
As there are multiple reasons as to why someone with ASD may wander, seeking support from a Behaviour Specialist is pivotal in understating the function/s and developing subsequent wandering-prevention strategies.

In addition to drowning, wandering brings with it other high risk factors, including but not limited to, exposure to the elements; dehydration; falls; hypothermia; traffic injuries; encounters with strangers and encounters with law enforcement.¹³

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58% OF PARENTS of children with ASD report wandering/eloement as the most stressful of ASD behaviours.¹²

NEARLY 50% of children with ASD are reported to wander.¹²

Wandering behaviour increases risk of INJURY OR DEATH.¹¹

74% of children with ASD will elope from their own homes.¹³
Although many individuals with ASD may have had swimming lessons and developed swimming skills, they may experience difficulties in using these skills across different environments (lakes for instance).

Difficulties with Generalisation:

Generalisation refers to the ability to transfer skills and information learned in one setting, to other settings, people and activities.

As previously indicated, drowning was the cause of approximately 90% of total (US) deaths reported in children with ASD (subsequent to wandering) ages 14 and younger in 2009 to 2011. 68% of these individuals died in a nearby pond, lake, creek or river.¹³
Lack of specialised services:

Training in ‘special needs’ has been available to swimming teachers for some time. However until recently, there has been a severe lack of specialised training for those with ASD and aquatics.

Swimming instructors need to understand how individuals with ASD process information and acquire new skill sets. Lessons for children with ASD need to be tailored to the strengths of the individual. There is also a need to incorporate components of water safety and water therapy into the lessons.
Many individuals with ASD have difficulties anticipating danger and judging risk.¹³

Difficulties with perceiving danger:

The risk of drowning increases with ASD severity. Many individuals with ASD have difficulties anticipating danger and judging risk.¹³

This is exacerbated if they also have an intellectual disability (which is the case for around 75% of individuals with ASD).¹⁴
Lack of awareness

Sadly, many in our community are unaware that wandering is even an issue or that drowning is such a high-risk for individuals with ASD.

In addition to parents and carers, there is very limited awareness in the general community about ASD, the attraction to water and wandering behaviour. Education for schools, first responders, healthcare providers and members of the community about wandering behaviour in ASD could significantly improve outcomes.

Only 50% of parents of children with ASD have received advice about wandering prevention from a professional.¹²
Access to prevention and response material is absolutely vital if the current drowning statistics are to be altered.

ADDRESSING THE CHALLENGES

Autism Swim’s mission is to ensure parents, care givers, community members and aquatic professionals have the necessary knowledge and practical skills on all things relating to wandering and drowning prevention.

John, a participant at one of Autism Swim’s surf awareness and modified nippers programs
To do this Autism Swim is continually developing resources and services. Examples of these include:

**Resources and services for parents:**

- Resource Toolkits
- Training
- Events
- Therapeutic Aids and Equipment Packs
- Behaviour Specialist Consultation

**Resources and services for Aquatic Professionals:**

Swimming instructors and aquatic therapists undertake a certification to become Autism Swim Approved. This means that they are equipped with training, resources, skills and support in order to most effectively teach their swimmers with other abilities. Autism Swim is the only certifying body for aquatics and ASD worldwide.

Autism Swim lessons encompass the following elements:

1. Water Therapy
2. Learn to Swim
3. Water Safety
## RESOURCES

<table>
<thead>
<tr>
<th>Resource</th>
<th>PARENTS</th>
<th>AQUATIC PROFESSIONALS</th>
<th>CHILDREN/ THOSE WITH ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wandering and Drowning Prevention Toolkit (the only one of its kind in Australia)</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Water Safety program syllabuses for therapists</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Water Safety colouring-in book</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>App - a water safety game developed in collaboration with parents, clinicians and those with ASD</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Available free from the App store in 2019</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘What to do when...’ sheets, with more than 15 scenarios</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>A suite of aquatic visuals, for the visual learners</td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Beach Safety and Pool Safety posters</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Lesson plans</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>PARENTS</td>
<td>AQUATIC PROFESSIONALS</td>
<td>CHILDREN/THOSE WITH ASD</td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------</td>
<td>-------------------------</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy and Psychology supports, such as calming resources, breathing exercises, yoga sequences and water therapy exercises</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Communication aids, such as Auslan and Key Word Sign reference sheets</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Social stories and aquatic supports</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Reward charts</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Spotlight sheets on conditions such as Dyspraxia, Low Muscle Tone, Attention Deficit Hyperactivity Disorder (ADHD), Fine and Gross Motor Skills, Motor Planning Difficulties, Bilateral Integration, Coordination Challenges and Skill Regression</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Educational blogs</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Terminology reference sheet</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

For access to the broad range of evidence-based and expert resources and blogs please visit [www.autismswim.com.au](http://www.autismswim.com.au)
“It’s a very loving, engaging and supportive community.”

- Simone, Parent within Autism Swim’s community
“Huge thank you Autism Swim for the swim instructor course. It was great to learn from experienced professionals about Autism Spectrum Disorder (ASD) and considerations I need to make in the aquatic environment. In fact, the knowledge and ideas I have gained have transformed the way I approach all of my swim lessons and students.

It was really convenient to able to complete the initial training online and in my own time. Receiving new and refresher material every month helps keep my training current. Anytime I have had a query or needed some extra support, Autism Swim has been there for me.

The wandering and drowning statistics for those with ASD are alarming and I am proud to be a part of the Autism Swim community who is helping to make a change.”

- Christine, Swim Instructor

“It’s been an absolutely beautiful experience. The waves and the water are so regulating for her from a sensory perspective. The Autism Swim training is helping her to become safe around water.”

- Yasmin, Parent of Dippers (modified nippers) participant

The content is captivating, beautifully delivered and effortlessly easy to follow. There is a plethora of outstanding information and experience, given with empathy, generosity and importantly, an easy format to take notes and replay as required.

This incredible resource with ongoing support and learning aids I would recommend to any Swim Teacher.

- Kellie, Autism Swim Approved Instructor
REFERENCES

1. Jones, S., Akram, M., Murphy, N., Myers, P. & Vickers, N., Community Attitudes & Behaviours Towards Autism; and Experiences of Autistic People and Their Families: General awareness, knowledge and understanding of autism and social isolation, AMAZE, 12 December 2018


Autism Swim aims to ensure that the COMMUNITY is educated on its role in keeping everyone safe and happy around water, and striving to ensure that inclusivity becomes the norm.

Special thanks to:
Voluntary Advisory Board members Alexandra Scott, Audrey Variyan and Cheryl Pettinau. Our graphic designer, Amy Smith. Those who produced the data sets, for making them available. Our Autism Swim Approved Instructors and the wonderful parents in our community, who know that their child is capable of great things.

www.autismswim.com.au
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