

## Improved Awareness within Care Systems may help prevent Family Breakdown

<b>How</b> 	<ul style="list-style-type: none"> <li>→ By <b>earlier detection</b> of Asperger's Syndrome in adult member of family;</li> <li>→ By <b>earlier provision</b> of supports for adults affected by Asperger's Syndrome and their families.</li> </ul>
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Families that once stood strong and proud,  
have experienced **erosion of resilience and capacity**  
due to the **presence of unidentified** characteristics of  
Asperger's Syndrome within an **adult member of the family**.

<b>Why</b> 	<ul style="list-style-type: none"> <li>→ No prior awareness or identification of neurological difference;</li> <li>→ Typical assumptions and expectations of relationships and family life;</li> <li>→ No knowledge of how to respond or negotiate effectively within marital or family situation when neurological difference is present;</li> <li>→ Professional help has often proved ineffective because our care systems are largely unaware and therefore unable to recognise the signs of Asperger's Syndrome being present in an adult member of a family.</li> </ul>
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<b>What</b> 	<p><b><u>Possible indicators of Asperger's Syndrome could include:</u></b></p> <ul style="list-style-type: none"> <li>→ Heightened sensitivity to sounds, sights, touch, food texture &amp; tastes, scents &amp; smells, emotional atmosphere;</li> <li>→ Aversion to or reduced capacity to cope with crowds or extended social interaction, noise &amp; chaos, change &amp; unpredictability, verbal confrontation &amp; emotional situations;</li> <li>→ Anxiety;</li> <li>→ Depression;</li> <li>→ Collecting, hoarding, narrow obsessive interests;</li> <li>→ Tendency to rely on order, routines and rules, without flexibility;</li> <li>→ Unusual priorities;</li> <li>→ Rapid changes in mood and emotion;</li> <li>→ Awkwardness with people and some social situations;</li> <li>→ Communication differences and difficulties*.</li> </ul>
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<b>What</b> 	<p><b>* <u>Difficulties and differences in communication can include:</u></b></p> <ul style="list-style-type: none"> <li>→ misunderstanding others and being misunderstood;</li> <li>→ misinterpretation of meaning;</li> <li>→ missing and misreading verbal and non-verbal signals;</li> <li>→ lacking language to explain or describe thoughts, feelings, experiences;</li> <li>→ strong ability to remember and recount factual information;</li> <li>→ interpreting communication and words literally;</li> <li>→ missing implied meanings and hints;</li> <li>→ focus on word usage and spelling rather than gist and meaning;</li> <li>→ may talk at length on topic of special interest.</li> </ul>
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## Erosion of Family Resilience and Capacity

<b>How</b> 	<b><u>Undetected Asperger's Syndrome may cause erosion of family resilience and capacity in the following ways:</u></b>
	<ul style="list-style-type: none"><li>→ confusion and lack of knowledge about how to respond;</li><li>→ communication difficulties impede negotiation &amp; conflict resolution;</li><li>→ increased anxiety for all family members;</li><li>→ adult with AS may impose own routines and preferences on others, particularly as personal anxiety increases;</li><li>→ frustration and fear;</li><li>→ fractured or fragile relationships between family members;</li><li>→ stress and exhaustion;</li><li>→ mental health problems, particularly chronic anxiety and depression;</li><li>→ as personal and family demands increase, adult with AS may either attempt to exert more control within the household or lose the capacity or will to sustain responsibilities, placing greater strain on the partner;</li><li>→ deterioration in parenting capacity;</li><li>→ loss of employment or employment opportunities;</li><li>→ social isolation;</li></ul>

## Autism Spectrum Disorders are a family affair

	<p>When a child is diagnosed with an Autism Spectrum Disorder, some families then go on to discover that one or both parents may also have some characteristics of Asperger's Syndrome, or vice versa. Parenting in this day and age is challenging for any parent, but particularly so if a child has a disorder or disability. Naturally, the challenge increases if one or both parents also have difficulties that could impact on their capacity to cope. Timely and appropriate intervention and support could make all the difference to a family's ability to cope, and may prevent the tragic and traumatic imposing of punitive interventions and Court Orders separating parents and children that can occur as a result of personal or family breakdown, particularly if Welfare and Court systems do not understand Asperger's Syndrome either.</p>
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It is unjust when a family, already called on to **accept the presence of an Autism Spectrum Disorder within the family,** is **denied supports and interventions when sought,** and then **punished for not being able to cope.**

**“Without an understanding of Asperger’s Syndrome,  
people make a moral judgment.”**

(Tony Attwood, 13 August 2009)

## **Family Breakdown**

<p><b>How</b></p> 	<p><b><u>Family Breakdown</u></b></p> <p>When any person or family lives with long-term confusion, conflict and stress, and is unable to access help when needed or sought, they can become frustrated and overwhelmed leading to the possibility of unfortunate and serious consequences, such as:</p> <ul style="list-style-type: none"> <li>→ inability to cope;</li> <li>→ anger and rage;</li> <li>→ breakdown and mental health problems;</li> <li>→ accidents;</li> <li>→ illness;</li> <li>→ domestic violence;</li> <li>→ risk to children;</li> <li>→ disintegration of family;</li> <li>→ divorce;</li> <li>→ legal battles;</li> <li>→ financial loss and disadvantage;</li> <li>→ self-harm and suicide.</li> </ul>
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## **Barriers**

	<ul style="list-style-type: none"> <li>→ <b><u>Barriers to adult with Asperger’s Syndrome receiving help</u></b></li> <li>→ Adults with the characteristics of Asperger’s Syndrome can be highly intelligent, even genius. It is not uncommon for adults with Asperger’s Syndrome to have highly recognised professional qualifications in fields such as Engineering, Medicine, IT, Science, Accounting, Law, Art, Film, Acting, Photography, Music, Languages, Academia, etc.</li> <li>→ <b><u>Society assumes consistency of intelligence in all areas of life and therefore has corresponding expectations.</u></b></li> <li>→ Adults with Asperger’s Syndrome may be eloquent and have strong skills in language and verbal expression but this can be misleading and prevent the detection of underlying difficulties with interpretation and processing.</li> </ul>
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	<p><b><u>Barriers to adult with Asperger’s Syndrome <i>receiving</i> help, Cont’d</u></b></p> <ul style="list-style-type: none"> <li>→ Adults with Asperger’s Syndrome may respond to a situation by withdrawing or by escalating verbally or emotionally. These reactions are typically interpreted as avoidance, obstruction or aggression, when in fact they may be signs of stress, fear, panic, feeling overwhelmed, not knowing what is expected of them or not knowing what to say or do. These reactions could also be an attempt to create distance or regain a sense of control in the midst of confusion and unpredictability. Physical restraint, raising voice or use of force will traumatise a person with Asperger’s Syndrome and will further increase barriers to appropriate help being provided.</li> <li>→ May have limited capacity for effective self-advocacy or securing access to other forms of advocacy or legal representation.</li> <li>→ Some behaviours may be incorrectly interpreted as criminal, harmful or obstructive;</li> </ul>
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	<p><b><u>Barriers to partner or family members <i>receiving</i> help</u></b></p> <ul style="list-style-type: none"> <li>→ neither they nor the care systems know about Asperger’s Syndrome;</li> <li>→ can’t adequately describe what is taking place in relationship or family situation and claims may be perceived as implausible;</li> <li>→ adult with Asperger’s Syndrome may be able to mask difficulties in public;</li> <li>→ care systems brush off, play down or interpret problems incorrectly;</li> <li>→ appropriate supports and services are simply not available.</li> </ul>
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	<p><b><u>Barriers to adult with Asperger’s Syndrome <i>seeking</i> help</u></b></p> <ul style="list-style-type: none"> <li>→ limited self-insight so may not recognise the extent of their difficulties;</li> <li>→ limited ability to recognise the impact their difficulties may be having on family members and others;</li> <li>→ fear of failure or being seen as defective;</li> <li>→ an historical experience of not being understood;</li> <li>→ communication and social difficulties may limit access to or compliance with services;</li> <li>→ fear of being bullied, rejected, exploited or discriminated against;</li> <li>→ may not realise that help is available;</li> <li>→ may have developed the belief that others have the problem, not them.</li> </ul>
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	<p><b><u>Barriers to partner or family members seeking help</u></b></p> <ul style="list-style-type: none"> <li>→ frustration and anxiety over inability to adequately articulate experiences and needs;</li> <li>→ belief, based on past experiences, that other people including care systems won't believe them and can't help them;</li> <li>→ instinct that family member with Asperger's Syndrome is innocent of intentionally causing harm;</li> <li>→ fear of being judged or punished for failures or mistakes;</li> <li>→ fear of having children removed by child welfare agencies;</li> <li>→ fear of reprisal from adult with Asperger's Syndrome or other family members for revealing family secrets.</li> </ul>
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**Improved awareness** within our care systems in relation to Asperger's Syndrome in adult relationships and parenting, and the **provision of appropriate supports or referrals**, will ensure that families are **assisted to re-build the resilience and capacity** they began with and **enable them to cope better** with the circumstances they have been dealt.

<p><b>How</b></p> 	<p><b><u>Assisting families to re-build the resilience and capacity they began with may be as simple as:</u></b></p> <ul style="list-style-type: none"> <li>→ belief in and support for family members seeking help;</li> <li>→ care systems trained in how to respond and support adults and families appropriately;</li> <li>→ referral to psychological services as needed;</li> <li>→ increasing societal awareness and understanding.</li> </ul>
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Extended version of ASPIA Advocacy Leaflet titled  
 “Improved Awareness within Care Systems may help prevent Family Breakdown”  
 Based on Poster prepared for Asia Pacific Autism Conference 2009 (APAC 09)  
 The information presented in this poster/leaflet has been gathered over the last nine years  
 and is based on the combined experiences of more than 1000 Australian families.  
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 ASPIA has been conducting support group meetings and educational workshops in Sydney since 2003,  
 as well as providing a helpline and website for information.  
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