



Family relationships and Autism Spectrum Disorder: Lived experiences of young people with autism and their families

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Study overview

- Lived experience research.
- Mothers, fathers, siblings and autistic young people shared stories about their family life.
- Key findings include:
 - **Identity** - How families perceive themselves.
 - **Relationships** - Impacts of autism on families' relationships.
- Implications include:
 - **Strategies** for strengthening family relationships.



Identity – Being different and feeling different to others

Many families and autistic young people shared how autism played a role in who they were and how they saw themselves. Three key themes illustrate their experiences of being different and feeling different to others.

Unique and different

- Unusual feelings and behaviours - **different to others**
- A skill or ability - **something special**



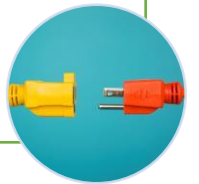
Intense emotions

- Stress, anxiety, anger - **not in control**
- Energy, focus, drive - **strong sense of self**



Disconnected and blocked off

- Disconnected - **in our own worlds**
- Unwritten social rules – **difficulty connecting**



Relationships - How autism impacts family relationships

- Disruptive and connective factors influence families' communication and coping style.
- When connective factors are more prevalent families often experience greater connectedness in their relationships.
- When disruptive factors are more prevalent families often experience greater disconnect in their relationships.

sharing memories
different perspectives
getting to know one another
establishing routines
checking in with each other
Connective factors
planning family activities
making time for each other
working as a team
communicating openly
reflecting

anxiety
annoyance
tiredness stress
different perspectives
demands and attention
misunderstanding reactions
Disruptive factors
misunderstanding behaviours
difficulty relating
violence caring role
anger frustration
swearing



Implications – Strategies for strengthening family relationships

Informed by the key findings, 6 broad elements for practice were generated that address some of the recognised impacts autism has on family relationships.

Communication

- Develop families' openness and communication with each other.

Education

- Educate families on adaptive patterns, e.g., coping and conflict resolution.

Recognition and awareness

- Encourage recognition and awareness of issues impacting family and relationships.

Cohesion and connectedness

- Promoting cohesion and connectedness amongst family members.

Autonomy and inclusion

- Promoting family members autonomy and encourage the inclusion of autism and disability throughout all family domains.

Active participation

- Strive to reduce powerlessness and external exclusion by reinforcing active participation in the community.