



NAVIGATING THE SERVICE SYSTEM

Neurodiversity and Substance Use



:TODAY

A lived experience perspective

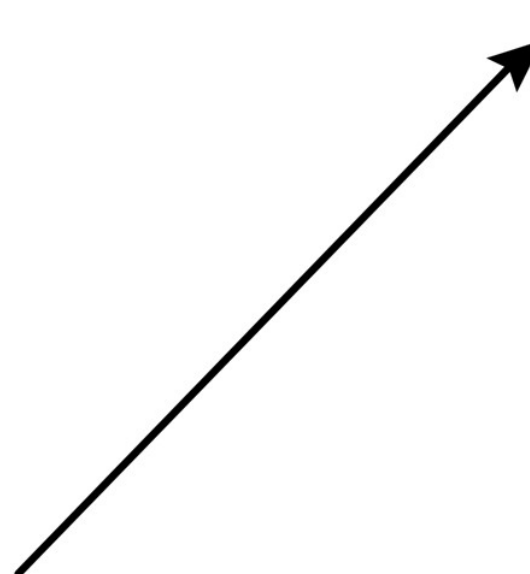
Medical model vs social model

To explain what it is like to try and access supports

What has worked

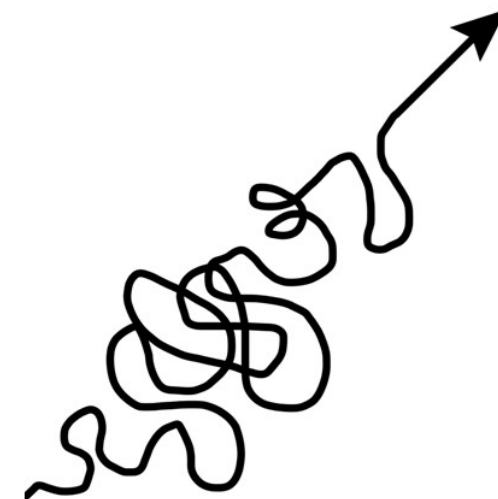
What i wished people knew

SUCCESS



what people think
it looks like

SUCCESS



what it really
looks like

Different Journeys

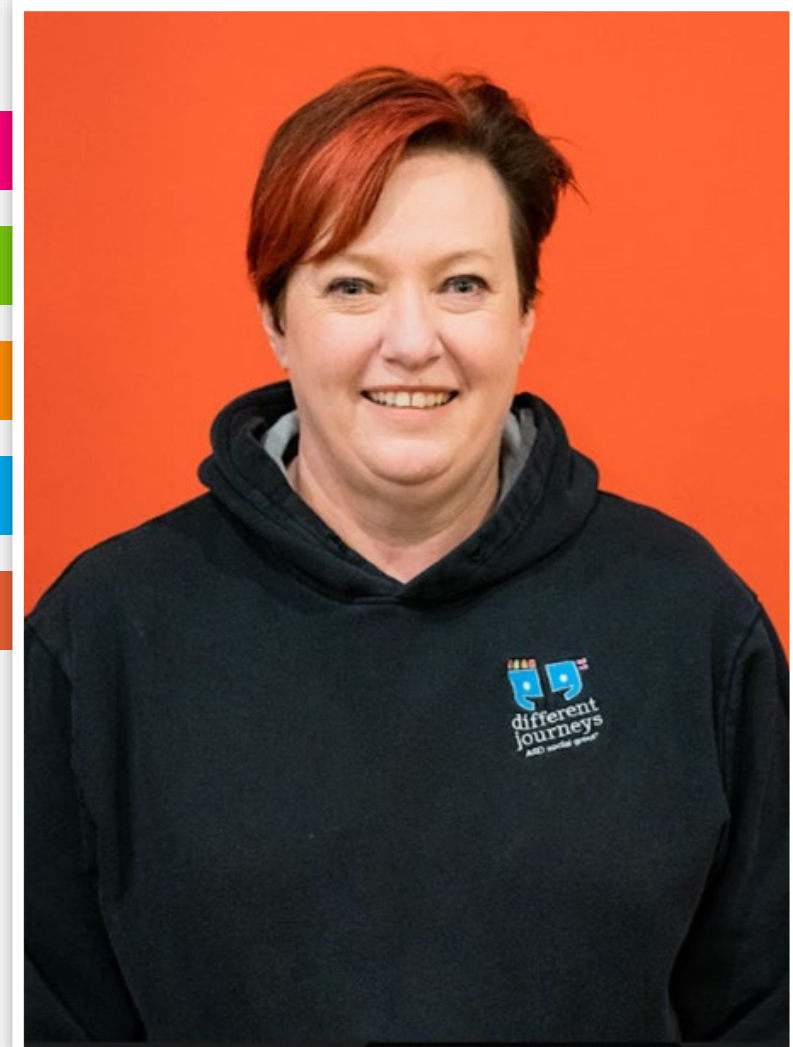
Proud autistic ADHD woman

Parent/Carer to 3 autistic adults

CEO/Co-founder of Different Journeys

Employer of autistic individuals and carers.

OAM



Who are we referring to



**Individual
needing help**



Family members



**Some of their support team
members**



Medical Model vs Social Model
constraints and which are we
operating on

Acknowledgements of Autism

86%

of Australians have
**contact with an
autistic person**



3:1

The current estimated ration
of autistic boys and men to
autistic girls and women

29%

of Australians believe
they know how to **support an
autistic person**

4%

of autistic people / families
agreed people in the community
**know how to support
autistic people**



50-70%

of autistic people also
experience mental health issues

Autism & Employment

Unemployment Rate of Autistics

31.6%

3x

the rate of
people
with a
disability

Employed Autistic individuals

45%

say their skills are higher than their job required in their
current role.

They would like to be working more.

Unemployed Autistic
individuals

54%

have never held down a job

This is despite
having the skills,
ability and the
desire to work.

6x

the rate of
people
without a
disability

There are currently
2.65 million
unpaid carers in
Australia

287,000
primary carers provide
40 hours or more
or more of unpaid care
per week

Carers provide
2.2 billion hours
of unpaid
care per year in
Australia

The replacement value
of the unpaid care
provided is
\$77.9 billion
per year in Australia



**Many don't even
know there are
supports
available**

Why are Carer supports important?

Research states caregivers of Autistic people experience:

- significantly greater stress than caregivers of other children with developmental conditions.
- significantly more emotional distress and are more likely to suffer serious mental health conditions compared to carers of people with schizophrenia.
- debilitating stigma, including being blamed for their child's deteriorating development, and often feel judged, excluded, avoided and/or pitied.



The Carer Journey – the lived experience

Issues facing Carers



The Diagnosis



**Same diagnosis but
different presentations,
the added in extras**

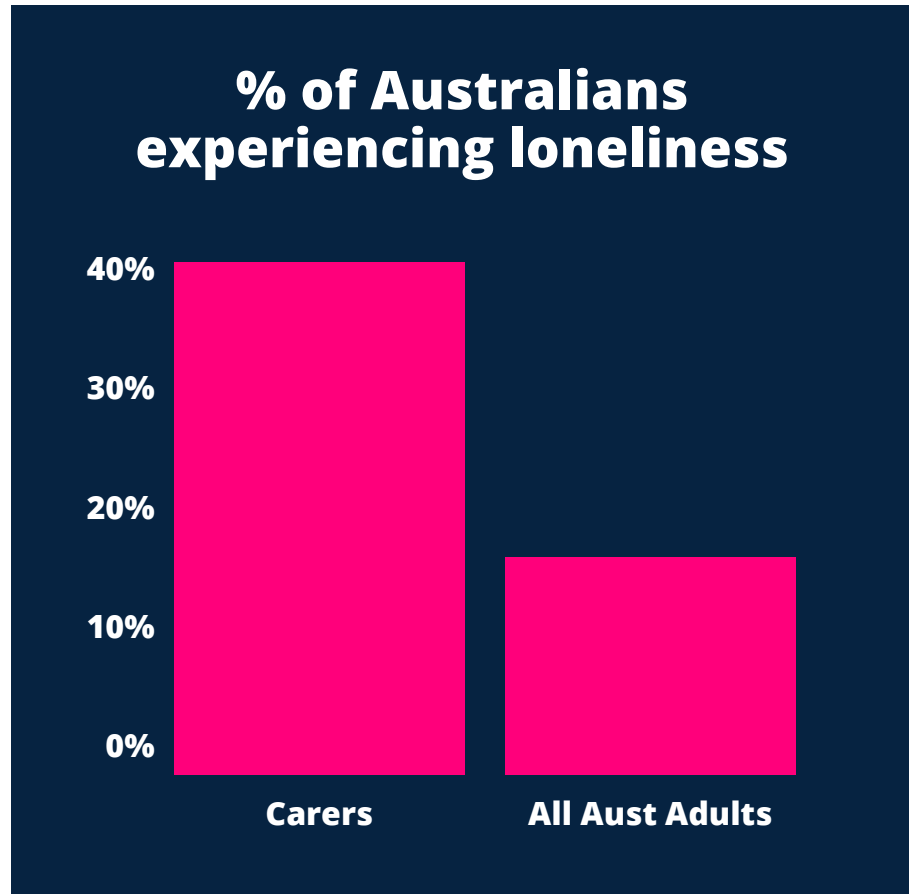


**Barriers faced by
the Carer**

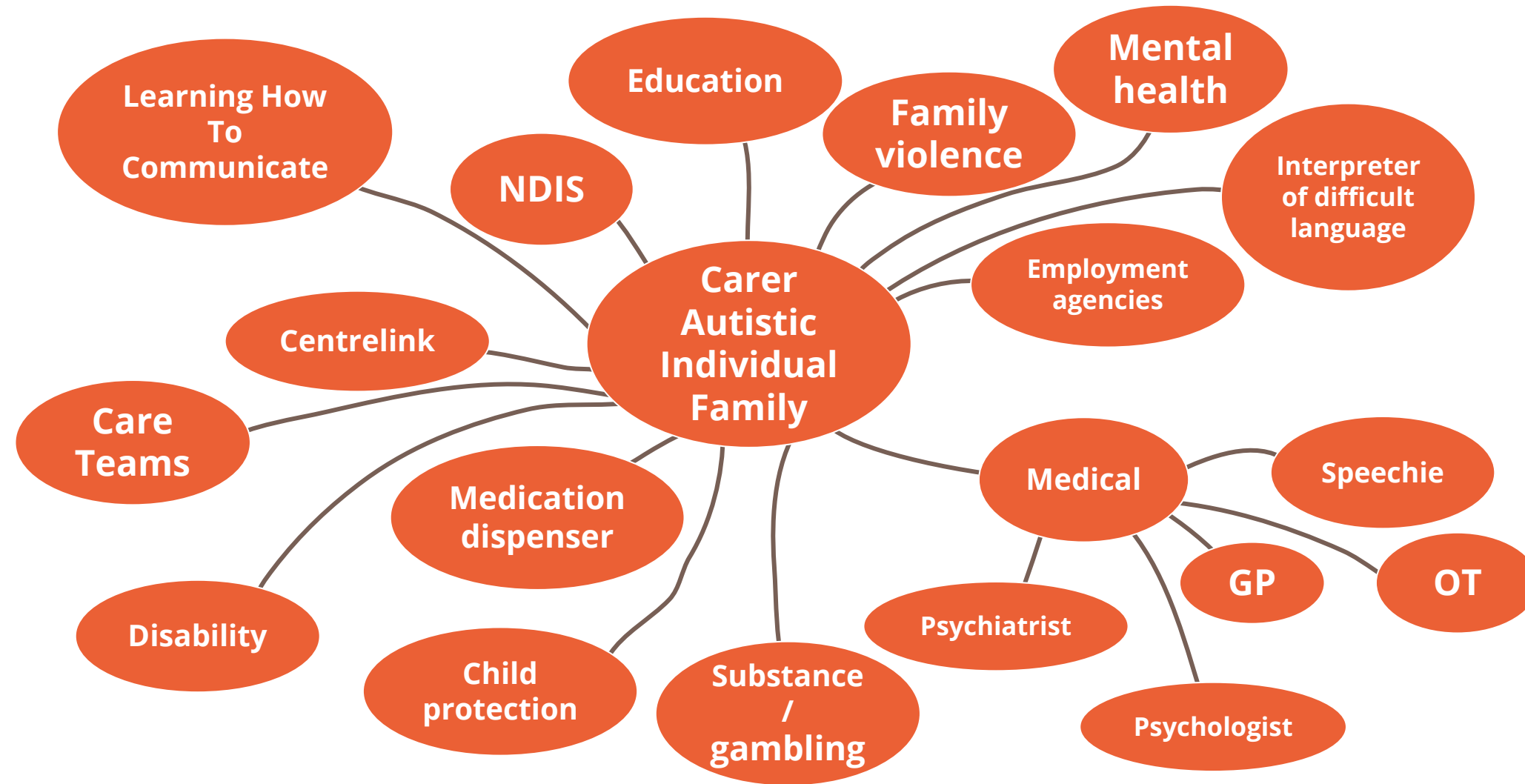


**Accessing the
support**

Did you know?



How many service systems am I dealing with



**MANY OF WHOM DO NOT
UNDERSTAND THE COMORBIDITIES
OF AUTISM AND MENTAL HEALTH
OR ADDICTIONS. WE ARE BEING
SHUNTED BETWEEN SERVICES.**

WHO SUFFERS?

IMPACTS

Increased
loneliness and
isolation

Poor mental
health

Homelessness

Relinquishment

Despondency

Family
breakdowns

Suicide ideation

Lower
economic
participation

Nowhere to go
to get help

Where do I find
out information

More reliance
on service
Australia
income

Frustration of
getting different
answers from
same agencies
particularly if
claim has been
rejected. Totally
reliant on person
at other end of
phone

How can you support?

- Acknowledge that the journey is hard.
- Never judge – just listen.
- Tell them that there is support available.
- Validate that we don't have all the answers.
- Ask permission to do a referral to another organisation for support (often we do not have the capacity or time to do it themselves if we give them a phone number, internet link).
- Model how to make a phone call, ask for support, question a decision.



Types of considerations that could be needed



**Ask what support
is required**



**Use clear, simple
language**



**Present one idea
at a time**



**Use visual supports such
as checklists and signs**



**Be aware of sensory
sensitivities**



**Accommodate
stimming behaviour**



**Allow processing
time**



**Give plenty of notice for
any changes in plans**

Flynn



HOPE



Different Journeys Model

Finding solutions instead of fixing the problem

How Can we find ways to support inclusion

Neurodiverse acceptance

Imagine the possibilities of being positive

focused rather than difficult



Different Journeys' Events Provide

A place for the autistic individual and their Carers to:



Feel Safe



Feel Accepted



**Feel
Empowered**



**Feel Connected
(part of a tribe)**

Different Journeys Vision

With the right investments and working together, imagine what is possible.

We have an opportunity to make this happen – and it has such a positive ripple effect which does not just focus on the person-centered approach.

Everyone needs a champion and people to believe in them.



What do i want to see

Imagine

a different world of

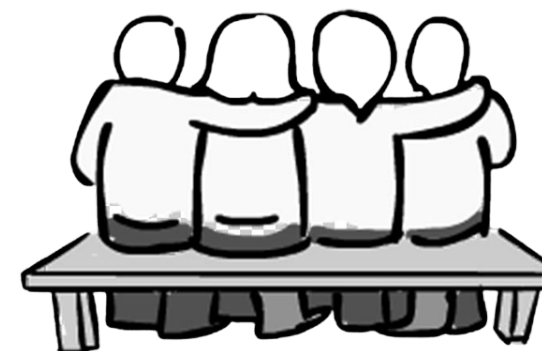
Acceptance

Understanding

Support



different
journeys
Empowering Autism



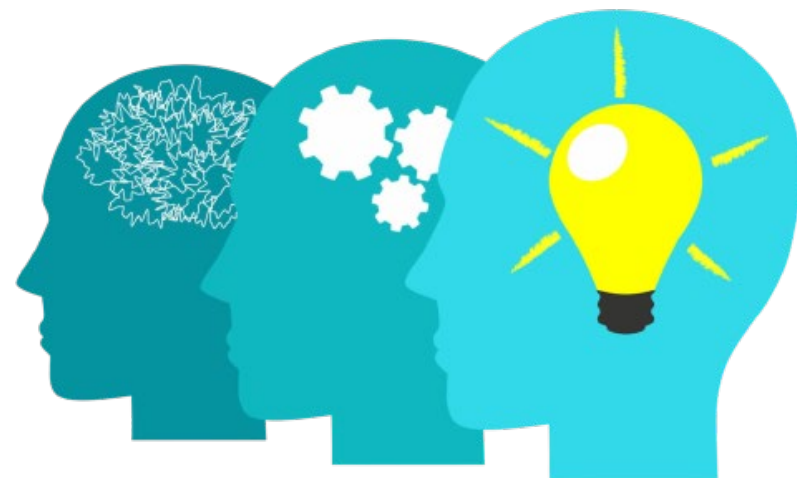
Remember:

“Reality to and autistic person is a confusing, interacting, mass of events, people, places, sounds and sights... Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear.”

- Jolliffe, et al (1992) in Howlin (2004), ibid, p.137.

Final Words

Each person does see the world in a different way. There is not a single, unifying, objective truth. We're all limited by our perspective.



[Siri Hustvedt](#)

Opportunities are endless. We just need to change our view