

Who I Am:

I have always struggled with not fitting in, feeling so different and confused by the actions of others, even within my own family.

I had never had a romantic relationship and was always anxious that people would find out how "weird" I was and reject me - a pattern that has played out again and again and I still don't know what I've done to upset people and explain the bullying, verbal and physical abuse, rejection and ostracisation that always occurs from people who say they want to be my friend.

I survived verbal, emotional and physical abuse from my siblings so I learnt to "hide myself" away, I was safer on my own and that I was never going to be accepted for who I truly was and how I behaved and thought and questioned the world. My mother

tolerated the abuse towards me as she was glad my brother and twin sister were "trying to change the behaviours" I exhibited. (I was finally told the truth of this this year once I'd informed my mother and sister of my diagnosis). My own father, who is dead now, told my siblings, grandparents and aunty, that he felt I wasn't his child because I was so "different" to my siblings and he and his siblings growing up. ~~and~~ My own mother rejected me too often because I was "too difficult" and "hard to love".

I decided to become a Primary School teacher to help any little child who was struggling like me so they would felt seen and appreciated - like a few wonderful teachers did for me.

SO I taught younger grades of Primary School and through me teaching/modelling social skills and values and positive kind behaviours, I also taught myself the simplest of social skills. **BUT** despite this I am still unable to successfully navigate and have friends, especially women. I know now I was masking and did it well to go unnoticed throughout High School and Uni but I knew I was trying to copy, fit in and be safe by blending in. It is exhausting and reinforced that my natural self wasn't good enough. but I never knew **WHY** ②

The WHYs of why I am like this, do this, feel this etc is what I need to learn in order to try to fill in the deficits I know exist...

- How my brain differs...
- Strengths I have ... things I need to develop...
- Physical things that are also affected by Autism.

I have been on anti-depressants since my early 20s when the reality of life and knowing in my bones I was different and struggled with things that others managed so easily/intuitively sunk in.

I turned to [REDACTED] for education, a safe place to be myself so I could hopefully make a friend and have things to look forward to do with people like me and supported by professionals who would help me develop the skills that I obviously lack; better understand what I might be doing to upset, annoy or aggravate people. I was hoping to finally get some answers and advice to alleviate this life-long torment. I want the support I was denied growing ~~the~~ up to try to bridge (3)

the gaps of the things that are still
in me now.

I got my hopes up that [redacted]
[redacted] would have programs designed
for late-diagnosis females (and males)
like me.

But I am saddened
to say that they don't.

A 'peer group' was the only
thing even directed/acknowledging
someone like me and, as described further on,
as I discovered was a huge
disappointment, no funding or
resources are allocated and it
was unstructured, uncomfortable,
too random, no autonomy on who
we were thrown in with. ~~There~~
~~should have~~. I went home - 2 hour drive
and felt so unseen, not valued and
recognised by [redacted], a waste of
huge effort to get there and time and (4)
hopeless that that was all we were offered

Why is all the support aimed at children with Autism?

I have spoken with several other adults I have met and we all feel to [REDACTED] we don't matter. Especially those of us with late diagnosis.

So much support is provided for autistic kids so they don't grow up with disabling deficits ...

Well we ARE those that have had to grow up without understanding how we are different, why we struggle in silence, blaming ourselves for being wrong, stupid and inept. All the support is spent on kids so they don't grow up with low self-esteem and self-confidence

BUT we are here. We are the lost ones. Who have had to traverse through life in the dark and with pitfalls so we were doomed to fail. We finally see the light, and told there ARE ANSWERS ①

So I, same as others I have spoken to,
turned to [REDACTED] with HOPE
for the first time in my life that I
would get help and understanding
and assistance on How to function
in this world ^{of people} our brains ~~were~~
grew differently too AND NOTHING.

- I had to wait over a year
to be ALLOWED to access a social
group of people like me. Where I
hoped my deficits ~~for~~ wouldn't offend
as it would be guided by professionals
who understood Autism, behaviours and
would work towards teaching us
things that we do that upset others etc
BUT no.

I drove for 2 hours to meet a
group of random individuals aged
from 30 - 84 years old with the only
thing in common was that we all
had ASD.

It was "Peer Led" with no
structure, no activities planned, no
name tags etc.

THE BLIND ^{IT} WAS THE BLIND LEADING

2 people with the same Autistic gaps in knowledge, skills and ^{unawareness} understanding were expected to lead a group.

WHEN THEY THEMSELVES lacked the skills, ~~to~~ awareness to ~~get~~ ~~be~~ to lead us we introduced ourselves, why we came. We ~~then~~ were sitting there waiting to be told/outlined what to do when one of the leaders entered a conversation with one individual. The rest of us were shrugging and asking "What do we do now?" "Is this it?" So were were confused, left to ourselves and ignored.

I was a Primary School teacher for nearly 20 years. ^{I did my post-grad study on group} PEER-LED groups only work if they are lead by people with EXCEPTIONAL interpersonal skills, highly empathetic, Exceptional communication skills and TRAINED with clear roles/responsibilities and resources.

In the year I wanted to even be able to meet others to see if I felt comfortable or liked anyone supposedly

PEER Facilitation was occurring. I saw NO evidence. ^{LEADERS GOT SUPPORT (I believe) BUT to the detriment of the needs of us the group} THE PEER

~~Again~~ ~~we~~ AGAIN I felt, as an adult with Autism I didn't matter to anyone. (3)

The way I saw PEER-LED meant 2 people got training and a chance to develop THEIR skills over the needs of us.

I wasn't worth [redacted] spending money to actually have framed professionals work with us. to guide us and help us gain skills so life isn't so hard.

We are the LOST ONES who ^{also} deserve time and resources to help make our lives better.

The 5 of the 7 of us who were able to speak independently

(1 woman had her mother, another young man needed prompting and scaffolding to speak)

All said we were there to LEARN about Autism. What we do that gets us into difficulties/conflict/bullying and rejection that we all had experienced.

• children who are recognised as ASD get help at school, psychologist help, help from their parents/caregivers who assist them to bridge gaps that the autistic child isn't aware they have etc. So they don't grow up LIKE US adults with late diagnosis

④ SO we need the help NOW that we were never given the opportunity to have. The children are the lucky ones.

I feel [redacted] has a responsibility and duty of care to those of us late diagnosed adults WHICH THEY ARE FAILING. ④

~~If I had~~ There are no resources near me. I accept that. But when I ~~did~~ overcome my anxiety, low-confidence, and summon the extreme energy to force myself to drive all that way, ~~find~~ ~~the~~ location, ~~find~~ a park etc TAXING things anyway BECAUSE I HOPED I would finally be able to spend time with people who could overlook my social deficits and ~~the~~ who ~~were~~ understood me. That I am a very kind and caring person who never means to hurt people, but somehow I seem to annoy or upset people and I'm always left so confused and hating myself even more...

To not warrant ANY professional support from [REDACTED] just reinforced my life-long feeling that I don't belong anywhere, I'll never be able to do fun things with others in a safe and relaxed environment. I cried for 3 days over the disappointment of waiting over a year for the opportunity to spend time positively with others and to ~~see~~ be told "There is no budget for this" ~~the~~ and that it was led by people who themselves weren't capable of ensuring we felt engaged, motivated etc. ⑤

• What I would like to see:

- online or in person seminars on ASD social behaviours - strengths - weaknesses and skill awareness ie - things to do to make others comfortable, - questions to ask

WE are like Jenga towers with large gaps and unstable foundations. WE NEED HELP TO FILL OUR SKILLS and understanding gaps so we can function better.



- Powerpoints or charts on the: • ASD brain

• sensory / physical / voice / things common to ASD that

- Learn about others / celebs / professors with ASD for positivity.

we aren't even aware we do.

- Workshops LED by psychologists / professionals where WE practice skill development through
 - a) role-play
 - b) videos and observations / discussions
 - c) questions ie what should/could I/they do if ...

- CREATIVE ACTIVITIES LED BY TRAINED professionals/volunteers (as I cannot get access to any in this state) ie Art Therapy

- group sessions to help us build self-confidence and self-esteem and FUN in a non-threatening environment. How CAN THEY possibly FILL ours?

- GAMES DAYS - board games / card etc are set up and we can participate but monitored and with non ASD facilitators.

MORE SUGGESTED ACTIVITIES:

- Outings set up for ANY to attend eg every 2-3 months. (Don't leave it up to us to organise etc. THESE ARE OUR DIFFICULTIES)

DON'T MAKE PEOPLE WAIT TO BE ALLOWED. WE ALREADY HAVE BEEN EXCLUDED ENOUGH IN OUR LIVES

- ie on the website say a date and a trip organised and we email/call to RSVP
- bush walk
- photography at the Botanical Gardens
- Trip to an Art Gallery or Museum
- Animal experiences
- Movies (cinema or even DVD at the centre)
- Picnic at a park with^{eg} Volleyball, frisbees, chess etc set up AND

facilitators to guide/support. AND OUTLINED WHAT will occur and HOW we can participate BEFORE-HAND so we can feel secure and choose to participate

My primary school teaching helps me see the potential of what COULD be done. Online activities, especially for us rural or people who don't like going out = zoom Trivia or Actionary or art - directed by someone but we are still socialising

The priority rather than the activity Itself IS: - we know what to expect of the event

Within these REGULAR events LEADERS with ASD can be mentioned and have more leadership roles BUT they must be supported by a professional - to ensure they are ok AND the needs of the group are met equally.

- it is guided/supported by professionals WHO do not have the deficits themselves.

- It is OPEN to anyone participating to come and see if there is a person they click with. NOT FORCED TO SOCIALISE with a tiny group SELECTED FOR US. ⑦

- The fact the groups are CLOSED to new people is already subjecting vulnerable people who have been ostracised TO MORE feelings of being isolated / alone and unwelcome.

- I imagine they are closed so the group participants get to know each other and the group isn't always changing

BUT what about the others who have been denied the ~~chance~~ opportunity to try?

Couldn't they eg. keep the group meeting as normal and open up a half-hour at the end where people CAN go along and try it out and see if it suits them? If there is anyone there they feel comfortable with or would like to see again?

There needs are being denied for the 6-7 who GOT SELECTED.

- I also think there should be PROCESS/METHOD and reasoning to the group selection/formation. I was placed with random others who the only thing I had in common with was ASD like animals thrown together in a zoo. I felt dehumanised ©

• Would you throw 6-8 random non ASD people together and say be friends? No.

↳ We have spent our whole lives not having friendship groups and social groups (unless enforced like at work)

AND we are still denied this by the way [redacted] functions for us as adults, with late diagnosis.

• That why it is imperative WE ARE GIVEN THE CHANCE to mix and formulate groups based on common interests AND the SET-UP ACTIVITIES ^{I propose} provide the opportunities for this to occur and hopefully friendships can form organically

E.g. [redacted] Has a few rooms to use for gatherings. Why isn't a day a month set aside for OPEN INVITATION and each room has a ^{different} activity and leader or 2 (can be the Peer Facilitators) BUT it must be overseen/supervised by a ~~non~~ ASD professional to a) ensure the peer facilitators are functioning and comfortable and b) the participants know they are professionally supported.

This would provide:

- autonomy/ freedom of choice for the participant

⊛ I would start the session with all together and SOME EDUCATION on autism in adults.

- STRUCTURE to relieve anxiety
- AGENDA/EXPECTATIONS described in the booking info before hand

INTRO activity THEN we can choose which activity to do...

(cont)

THEN from those initial sessions
like-minded people can say they'd like
to do an outing or activity next time

⊕ Why aren't we worth spending
money on like the kids?

- Why do they get Centres/space
built for them to develop social skills
etc

BUT we don't?

- ASD kids get to do arts make things have time
and resources spent on BUT WE DON'T?
- Why do kids get to do art/mas
therapy and we don't?

• ALL OF THIS NEGLECT RE-INFORCES
what we've carried our whole lives - THERE IS NO
SPACE FOR US.

⊕ I WOULD GET just as much,
if NOT MORE out of regular
interest based events as I've
been previously denied if/access

to spend time in a supportive/safe/
encouraging space with others like me
who've never fit in and blamed ourselves
our whole lives and ONLY IN ADULTHOOD
are told we have REASONS for our struggles..
BUT THEN ABANDONED by the very organisation (10)
we are told to turn to.