



**ASKING
FOR HELP**

**IS A SIGN
OF STRENGTH**

**JEANETTE PURKIS AUTISM BOOKS
AND OTHER THINGS**

Disability services -
a first-hand
perspective

Jeanette Purkis

About Jeanette

- ❖ Autistic self advocate
- ❖ Author
- ❖ Public speaker
- ❖ Mentor
- ❖ Boards and representation
- ❖ Media
- ❖ Awards
- ❖ Public servant since 2007





The journey to here

- ❖ Difficult childhood
- ❖ Negative focus
- ❖ No diagnosis
- ❖ Early adult life - Errors, poor choices, exploitation
- ❖ Two diagnoses in twelve months
- ❖ Five lost years

The journey to here

- ❖ 'Ordinary'
- ❖ University
- ❖ Employment journey
- ❖ Poverty and no choice
- ❖ A mentor and a book
- ❖ A most unlikely - and grateful - public servant

Supports used

- ❖ Family
- ❖ Medical and mental health services
- ❖ Autism peak organisations
- ❖ Autism-specific employment service
- ❖ Self advocacy
- ❖ Social and friendship support



Impacts of positive service experiences

- ❖ Helped me build on strengths
- ❖ Gave me confidence to take on challenges
- ❖ Validated me
- ❖ Increased my trust in providers
- ❖ Enabled me to do the good things I do
- ❖ Supported my identity and selfhood

Impacts of negative service experiences

- ❖ Increased mistrust and with it negative focus
- ❖ Compounded issues rather than addressing them
- ❖ Took my sense of power and agency
- ❖ Increased my sense of 'us and them'
- ❖ Made me less likely to access services again

**I AM NOT A
PUZZLE TO BE
SOLVED. I AM A
HUMAN BEING. I
HAPPEN TO BE
AUTISTIC**

Jeanette Purkis' Autism Books
and Other Things.

Common issues in services

- ❖ Fitting the person to the label, not the label to the person
- ❖ Assumptions and stereotypes
- ❖ Paternalism
- ❖ Unhelpful 'assistance' and advice
- ❖ Apathy and disinterest
- ❖ 'Us and them' attitudes

What does a good service look like?

- ❖ Genuine listening
- ❖ Working together - on same team, for same goal
- ❖ Care and investment
- ❖ Services help rather than hinder progress
- ❖ Respect

How to improve services

- ❖ People with disability and / or family on Board, advisory committee etc - AND they are listened to
- ❖ Use criticism and complaints to drive change
- ❖ Open and accountable
- ❖ Supportive workplace for service provider staff
- ❖ See work as supporting and empowering rather than 'doing for' and controlling
- ❖ Be aware of impact of unspoken attitudes

How to improve services

- ❖ See each individual as an individual
- ❖ Be well-educated in the condition/s you support
- ❖ Listening and hearing
- ❖ Ditch the judgement
- ❖ Give individual and / or carers as much agency as possible around the service they are accessing
- ❖ Be aware of issues within the disability community

Questions?

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