



MENTAL HEALTH ADVOCACY PROJECT

Sarah MacDonald (Project Worker)

Community Living Association, Brisbane

PRESENTATION OUTLINE

1. Background to the Project

2. Research Method

3. Findings

4. Implications & Recommendations



COMMUNITY LIVING ASSOCIATION, BRISBANE

CLA MENTAL HEALTH ADVOCACY PROJECT

- **Aim:** Gather stories of assisting a person with intellectual or cognitive disability to access mental health services; to inform CLA advocacy.
- **Rationale:** CLA practice demonstrates persistent difficulty accessing appropriate mental health supports for people with intellectual and cognitive disability.

METHOD

12 interview participants	9 service providers
	2 parents
	1 self-advocate

Semi- structured interviews	General information
	Mental health information
	Accessing mental health services and support
	Outcomes of support
	Reflection on support and gaps

Data Analysis	Thematic analysis of interview data
	13 written case studies

CASE STUDIES



CS	Name	Sex	Age	Disability	Mental Health Conditions	Diagnosis	Interview Participant
1	Marcus	Male	22	Autism Intellectual Disability	Possible OCD Tourette's Depression	Not diagnosed	Service Provider
2	Ryan	Male	27	Intellectual Disability	Agoraphobia Anxiety Depression	Diagnosed	Service Provider Service Provider
3	John	Male	19	Autism (non-verbal)	Violent "tantrums"	Not diagnosed	Parent
4	Louise	Female	47	Intellectual Disability Developmental Delay (child)	Schizophrenia Personality Disorder	Previously diagnosed	Service Provider
5	Patrice	Female	-	Intellectual Disability	Depression	Diagnosed	Service Provider*
6	Kyle	Male	19	Intellectual Disability	Schizophrenia	Diagnosed	Parent
7	Mary	Female	23	Intellectual Disability	Schizophrenia Depression	Diagnosed	Service Provider
8	Dianne	Female	-	Intellectual Disability	Schizoaffective Disorder Schizophrenia Bipolar Disorder	Previously diagnosed	Service Provider
9	Jasmine	Female	32	Intellectual Disability	Depression	Diagnosed	Service Provider*
10	Joan	Female	47	Intellectual Disability	Delusional Disorder	Diagnosed	Service Provider
11	Len	Male	Mid 30's	Intellectual Disability Autism	Schizophrenia	Previously diagnosed	Service Provider
12	Simon	Male	-	Autism (non-verbal)	OCD Depression Anxiety	Previously diagnosed	Self-Advocate
13	Gia	Female	21	Intellectual Disability	Withdrawal Loss of function	Diagnosis not shared with Service Provider	Service Provider*

FINDINGS: 3 KEY THEMES



Identifying Mental Health Issues

Recognising Signs

Responding to Risk

"In the past five years Marcus hadn't left his room, except to go to the toilet. He hadn't changed his clothes in two years. When he got a vomiting bug he showered in his clothes and let them dry...The Acute Care team accepted the referral and a clinician and registrar visited the family...The post visit comments were 'Nothing wrong. Unkempt, long nails, odorous. Typical presentation of Intellectual Disability'." (P2)

"Patrice was living with her partner and his parents. Her partner was in jail for drug offences and Patrice was sexually assaulted by her partner's father. Patrice told her partner's mother who beat her then dumped her at the front gate of Patrice's mother's house. Patrice took on the blame, then denial of the sexual assault. They would find her sitting and rocking under a hot shower." (P5)

Accessing Mental Health Services

Multiple
Pathways

Complex
Processes

"John's father has taken him to the GP two or three times to get help with his behaviour. The GP prescribed an antidepressant. This medication has not helped and the GP has said she will refer John to a psychiatrist who can prescribe other medication. I don't know when this is going to happen. The GP has said she'll get back to us once she finds the right specialist." (P3)

"A Mental Health Tribunal Meeting was scheduled for one month after Joan's discharge to evaluate the reasons for the Intensive Treatment Order. Joan and her parents were not informed about this until they received a letter saying the meeting was the following day...Maree refused to attend, saying she would not understand a single word from the 'professional people'." (P10)

Getting Support in Mental Health Services

Accessing Resources

Quality Practices

"The doctors are focussed on the cost of hospitalisation, [but] there's a cost to all the services visiting but it doesn't help. Mental health wards don't have the capacity to hold anyone, no room or beds. They said she "wasn't suicidal" so they couldn't admit her. They said she needs to demonstrate "constant talk and valid gesture." (P8)

"The staff at [Hospital] said they were worried that because of her disability Mary would 'copy' other patients, which would make it difficult for them to assess her. They also commented on Mary having autism, which she does not. [Mary's mother] says the staff had no understanding of dual intellectual disability and mental health conditions." (P7)

"I was advised by an older nurse to find a place for Kyle and put him away and forget about him." (P6)

IMPLICATIONS & RECOMMENDATIONS

Findings:

- Consistent with existing research on PWICD and DD
- Identify persistent barriers for effective support to PWICD in mental health services.

Recommendations:

- Individuals and Significant Others
- Mental Health Professionals
- Service System

RECOMMENDATIONS FOR CHANGE

Individual & Significant Others

- Build Knowledge
- Increase Support

Mental Health Professionals

- Build Knowledge
- Develop Practice

Service System

- Targeted Frameworks
- Responsive Models



Sarah MacDonald (Project Worker)
Community Living Association, Inc.
smacdonald@communityliving.org.au