

# Gateways and Gatekeepers:

A co-designed and evidence-based investigation  
into the experiences of people with episodic  
mental illness during transition to the NDIS

2nd Annual NDIS and Mental Health Conference  
Presentation 31<sup>st</sup> October 2018

## Presenters:

Lived experience experts

Judith Drake & EbonyRose Lyons

Lead investigator

Elizabeth Hudson, PhD candidate



FUTURE  
SOCIAL  
SERVICE  
INSTITUTE

700,000

Australians live with **severe** mental illness



64,000

will be **NDIS** eligible



**Up to 91% NDIS ineligible**

will rely on non-NDIS community mental health supports

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### Presentation outline

- Introduction – meet the presenters: **Ebony, Judith & Liz**
- Background to the research project
- Research Advisory Panel
  - co-design & collaboration
  - contribution of panel
- The interview process & Results
- Research impact

## Explanation of key terms

**Episodic**

### Psychosocial disability

*Psychosocial disability highlights the social consequences of disability for people experiencing mental illness, as distinct from psychiatric disability, which focuses on the medically defined illness or impairment.*

National Mental  
Health Consumer  
and Carer Forum  
(2011)

### Personal Recovery

*Personal Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.*

Bill  
Anthony  
(1993)

# NDIS and mental health: The issues



## THE AUSTRALIAN

### Mental health in NDIS a 'mistake', says Patrick McGorry

Patrick McGorry,

RICK MORTON THE AUSTRALIAN 12:00AM April 6, 2017

The last-minute decision to include mental health support in the \$22 billion National Disability Insurance Scheme was a costly, dangerous mistake that should be unwound before lasting damage is done, says the nation's leading mental health advocate.

Patrick McGorry, a clinician and former Australian of the year, told *The Australian* the mental health sector should never have been shoehorned into the NDIS because it was a "completely different model".

NEWS | POLITICS

### NDIS Causing 'Growing Catastrophe' For Victorians With Severe Mental Illness

A new report has estimated that 90 per cent of Victorians living with severe mental illness will be worse off under the National Disability Insurance Scheme, with vital community support services set to be decommissioned to fund the initiative.



**National Disability Insurance  
Scheme (Becoming a Participant)  
Rules 2016**

made under sections 22, 23, 25, 27 and 209 of the  
*National Disability Insurance Scheme Act 2013*

## Part 5 When does a person meet the disability requirements?



- 5.1 The Act sets out when a person *meets the disability requirements*. The requirements are met if:
- (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or to one or more impairments attributable to a psychiatric condition; and
  - (b) the person's impairment or impairments are, or are likely to be, permanent (see paragraphs 5.4 to 5.7); and
  - (c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities: communication, social interaction, learning, mobility, self-care, self-management (see paragraph 5.8); and
  - (d) the impairment or impairments affect the person's capacity for social and economic participation; and
  - (e) the person is likely to require support under the NDIS for the person's lifetime.

# RESEARCH PROBLEM

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## 1. Personal recovery alignment

The terms **permanent impairment** and **a mandate for life time support** (embedded in NDIS legislation as preconditions for determining eligibility) are perceived by mental health advocates as incongruent with recovery principles.

## 2. Access and equity

Restrictions to access, detailed in NDIS rules, potentially exclude marginalised and hard to reach populations and those experiencing fluctuating mental illness.

## 3. Gaps/resourcing

Is the NDIS adequately resourced to meet the needs of people with psychosocial disability?  
Existing services are being replaced by the NDIS.

# RESEARCH PROBLEM → RESEARCH QUESTIONS

How are people with episodic mental illness affected by the NDIS scheme's design and governing processes?

## Problem 1

How is access to the NDIS negotiated and understood, by both NDIS industry professionals and people experiencing episodic mental illness?

## Problem 2

What are the structural barriers to and facilitators of social inclusion and recovery, and choice and control in the NDIS for people experiencing episodic mental illness?

## Problem 3

What are the social justice and well-being impacts of NDIS access and eligibility determinations for people experiencing episodic mental illness?

# What does the literature tell us?

## Inclusion and Recovery

Despite the enthusiastic uptake of recovery policy internationally, there is little research regarding the impact of self-directed support (like the NDIS) and recovery<sup>1</sup>

## Choice and control

Market logic assumes that competition will generate services, sufficient in both quality and scope to satisfy the needs of the consumer<sup>2</sup>

## Access and Equity

Only **81.4 %** of NDIS applicants with psychosocial disability are **eligible**. This compares to **97.5%** for people with other disabilities<sup>3</sup>

1. Slade, 2012
2. Fawcett & Plath, 2014
3. Joint Standing Committee 2017 report inquiry into the NDIS

## Identifying a research space for the project

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As the NDIS is still embryonic in its development, it is timely whilst the scheme is progressing toward full roll out in 2019, to examine the experiences of people with psychosocial disability for whom there may be service delivery gaps.



2 x mental  
health research  
professionals

## Research Advisory Panel

2 x lived  
experience  
experts

Investing in the Value of Lived Experience

*“It is our right to be involved in publicly funded research: to have a say in what is researched and in how it is carried out. If research in the twenty-first century is to be relevant, practicable and useful to the furthering of health and social care developments, then surely it has to involve the people who are at the receiving end of health and social care provision”. Mental health service user and researcher, Alison Faulkner (2011, p. 51).*

1 x NDIS rep

# THE RESEARCH PROCESS

Input from research Advisory Panel

2016



Recruitment  
of interview  
participants

2017



Interviews

2018



Interview  
analysis

Oct 2019



Draft thesis  
and plain  
language  
report

Dec  
2019



PhD Thesis  
submission

# Recruitment of research participants

7 x NDIS ineligible  
People with  
psychosocial disability

13 x NDIS eligible  
People with  
psychosocial disability

10 x NDIS  
professionals  
(Planners & Local  
Area Co-ordinators)



# Qualitative interviews

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## Topics/questions

informed by the Research Advisory Panel, literature review and researcher's background and experience

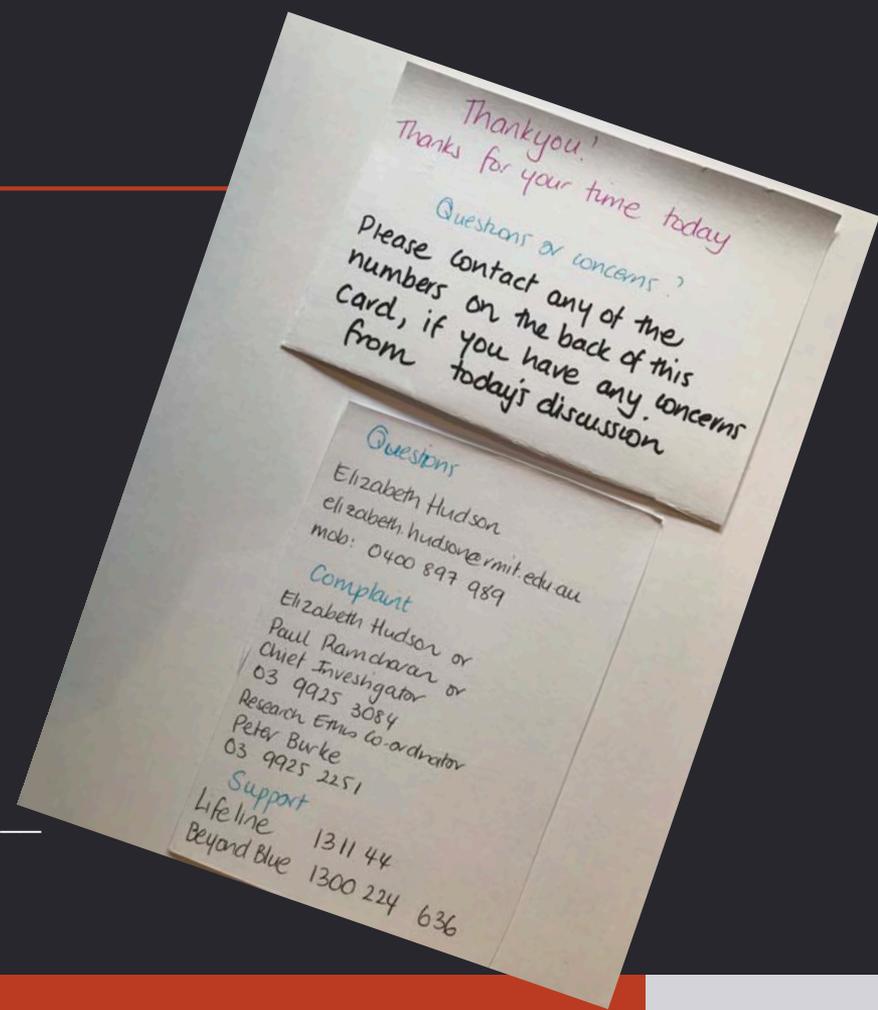
- social inclusion and recovery
- choice and control and
- access and equity

# Interviews

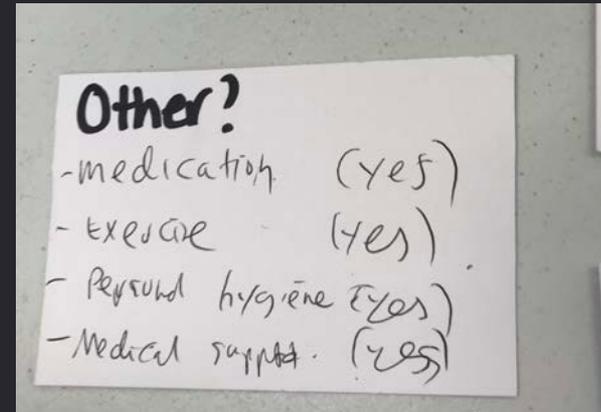
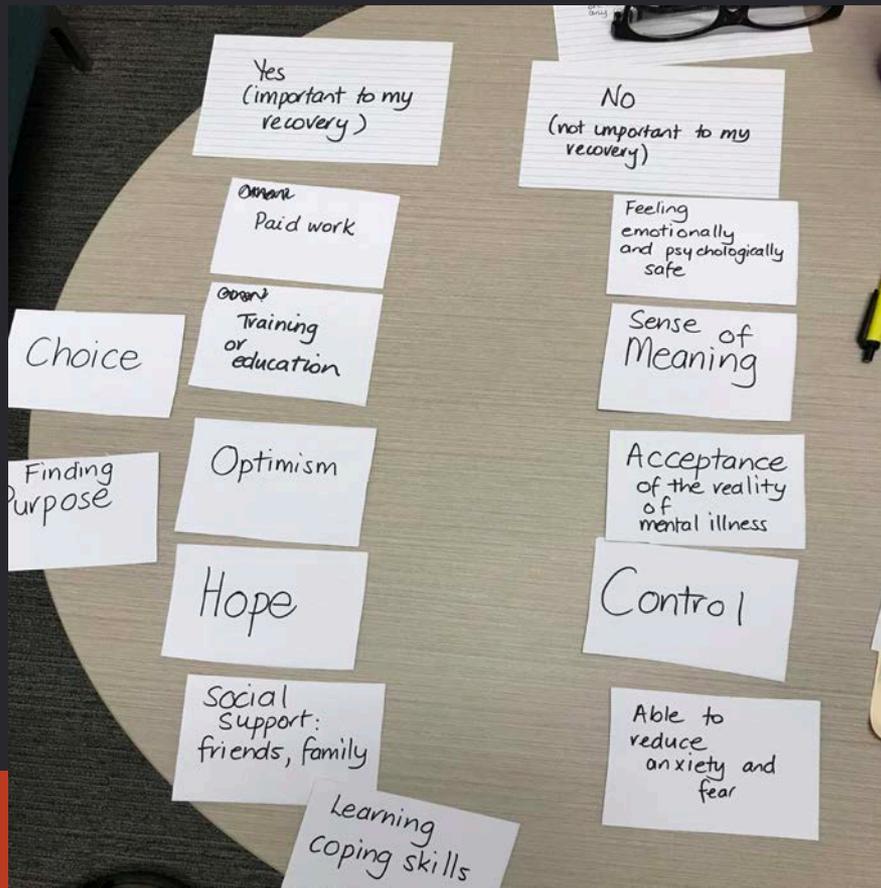
## Demographic questions

18. Do you identify with having any of the following mental illnesses or disability. You may select more than one:

- mood disorder - bipolar disorder
- mood disorder - depression
- anxiety disorders
- personality disorders (such as borderline personality disorder)
- psychotic disorders (such as schizophrenia)
- eating disorders
- trauma-related disorders (such as disassociative disorder/post-traumatic stress disorder)**
- substance abuse disorders.
- Other, please list \_\_\_\_\_
- Unsure
- Prefer not to answer



# People experiencing mental illness Interview guide recovery goals flash cards



## NDIS Professional Interview guide- scenario

Describe how you support a person through the planning process (refer to the following scenario)

*Lenny is a 40 year old male, recently divorced. He lives alone, He experiences periods of debilitating depression associated with his mood disorder. During these periods, he finds it hard to leave the house and he can go for days without attending to self-care, daily living activities or having any human contact. His depression is exacerbated by feelings of loneliness and despair.*

*He wishes to reduce his loneliness by establishing a circle of support and engaging in part-time employment.*

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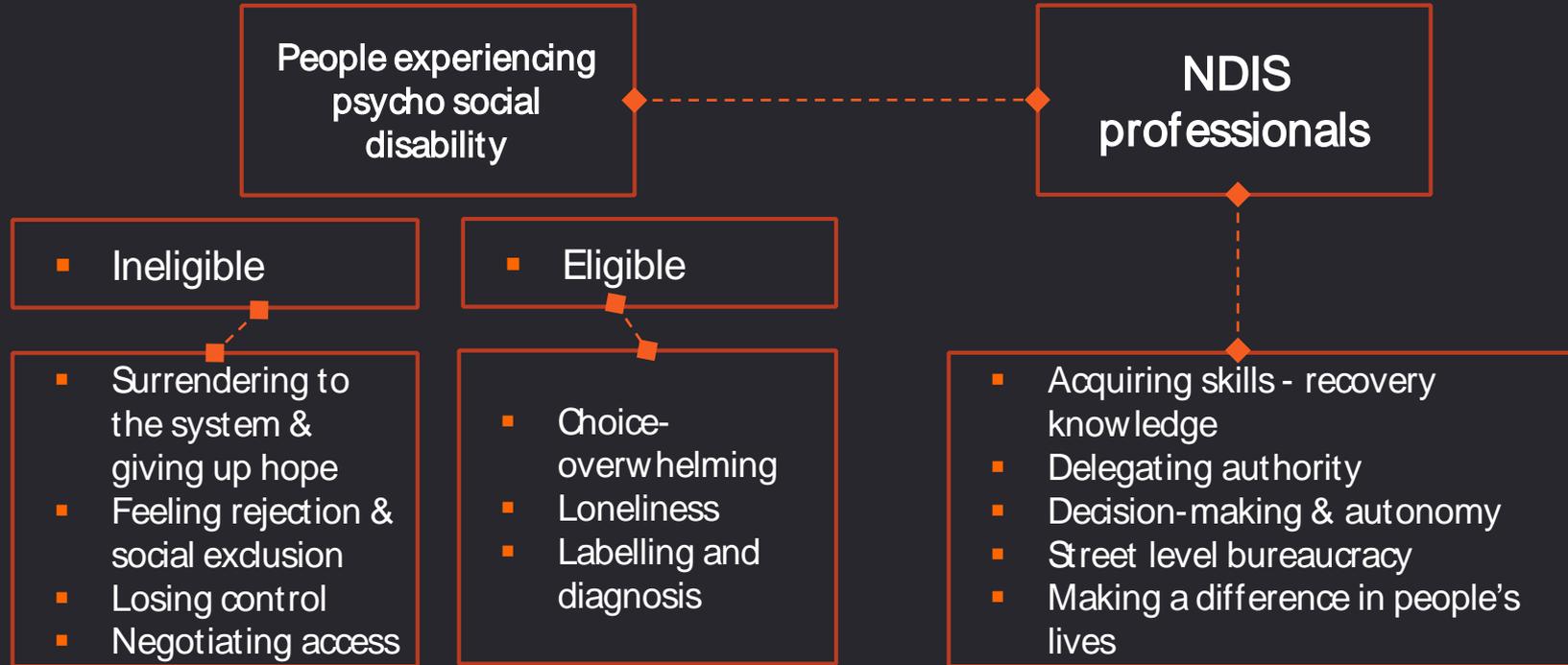
*“I think it’s [the NDIS] increased my stress and anxiety  
and fear.. .*

*I’m not looking forward to my assessment review. I’m  
not sure who’ll be supporting me any more. I just fear  
that my best interests aren’t being looked after. I feel  
like I’m **losing control** in my own therapy.”*

*Andrea, NDIS participant*

# PRELIMINARY FINDINGS from participant interviews

## Emerging themes



## Research Aims:

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- generate insights for future policy and practice by highlighting the consequences of NDIS design, rules and regulations and eligibility determinations for people with mental illness
- contribute new knowledge regarding access and equity in the National Disability Insurance Scheme

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*“I hate weekends and I hate holidays, [but] I love Mondays because it means there's Sprout, it means there's hope. And without Sprout..... literally not a lot of hope there”.*

*Cathy, NDIS ineligible applicant*