WHAT THE RESEARCH SAYS ABOUT SUPPORTING LGBTQ+ PEOPLE WITH INTELLECTUAL DISABILITY

SOCIAL IDENTITY IN EVIDENCE-BASED DISABILITY SUPPORT

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ACCESSIBLE PRIDE PROJECT

- Two-year initiative (2024 – 2026) funded by the Australian Government Department of Social Services through the ILC Program. Victorian focus with national relevance for inclusive practice.
- Consortium partners:
  - Inclusion Melbourne (systemic advocacy body, disability support provider)
  - Thorne Harbour Health (LGBTIQA+ community-controlled organisation)
  - ARCSHS (La Trobe University)
- Employs a Participatory Action Research (PAR) model integrating lived experience experts, subject-matter experts and organisational partners.
- Incorporates learning from past work with Deakin University, the Rainbow Inclusion Project, and research into conversion (change or suppression) practices in Australia.

PERSONHOOD, CITIZENSHIP AND IDENTITY

- **Personhood:** Described in disability-rights and SDM scholarship as relational, emerging through recognition, support and interdependence (Arstein-Kerslake et al 2021; Chalachanová et al 2021; Watson 2023).

- **Citizenship:** The outward expression of personhood through rights, belonging and participation in social, cultural and political life (Bach 2017; Duffy 2017; Stainton 2017). It involves agency, but also connection, contribution and recognition within the community.

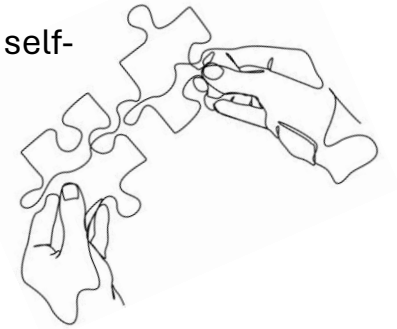
- **Identity:** An evolving sense of self (and self-concept) formed through relationships, participation and periods of exploration and commitment, including integration and consolidation of internal and social attributes like culture, sexuality, class and gender (**Falk & Sansour 2024**; Rodriguez et al 2023; Wofford et al 2022; Rękosiewicz 2020).
  - **Sexual and Gender Identity:** Integral to self-concept and wellbeing, yet often unsupported in practice (O'Shea & Frawley 2020; Sommarö et al 2020).

WHY DOES IDENTITY MATTER?

- Identity is a crucial part of how people interact with the world and is produced through a complex interplay between social structures and systems of meaning.
  - Many different types of identity exist. In this context, we're chiefly concerned with social identity.

- Sociologically, identity shapes how people are seen and treated by others.
  - Social identities mark the social boundaries through which power, privilege, and marginalisation are produced and maintained.

- Psychologically, identity is an immutable component of self-hood.
  - Developing a stable and positive sense of identity — being able to see and accept oneself — is central to wellbeing and self-determination.



- Collectively, social identities are important both internally and externally.

- Identity functions at an implicit level: even when people profess not to "see" race, gender, or disability, these categories still structure their perceptions, assumptions, and behaviours.

- Intellectual disability often considered a totalising identity, one that eclipses or overrides other aspects of personhood.

IDENTITY IN EVIDENCE-BASED SUPPORT PRACTICES

How do key evidence-based practices used in the Australian context incorporate identity considerations?

Supported Decision Making:

- International rights-based framework grounded in CRPD Article 12. Affirms universal legal capacity. Promotes supported rather than substituted decision-making (ALRC 2014; Flynn & Arstein-Kerslake 2014)
- Conceptualised as relational – decisions expressed through trusted supporters who know the person (Arstein-Kerslake et al 2017; Bigby & Douglas 2015)
- "Knowing the person" includes history, relationships and self-concept as context for will and preference (Bigby & Douglas 2015; cf. **Falk & Sansour 2024**)
- Communication and relational supports used to realise autonomy across life areas (Watson 2023; Wofford et al 2022)
- SDM literature links practice to agency and personhood development (Arstein-Kerslake et al 2017; Watson 2023)

Little explicit attention to **the application of SDM as a granular practice** to early identity exploration or consolidation, particularly in the 'core attribute areas' of sexuality, gender, culture, spirituality.

IDENTITY IN EVIDENCE-BASED SUPPORT PRACTICES

How do key evidence-based practices used in the Australian context incorporate identity considerations?

Positive Behaviour Support:

- Global applied behaviour framework integrating person-centred and rights-based values (Gore et al 2013)
- Focus on quality of life, inclusion, and reduction of restrictive practices (Gore et al 2013)
- Behaviour understood through interaction between individual and environment, with strong emphasis on unmet needs, autonomy, and importance of relationships (Gore et al 2013; Fisher et al 2025; LaVigna & Willis 2012).
- Holistic assessment requires attention to history, trauma, social context, unmet needs (NDIS PBS Capability framework; NDIS Practice Standards).

However:

- NDIS PBS Capability Framework and NDIS Practice Standards: omit sexuality, gender identity, and related self-defining factors. This omission weakens the intent to address unmet needs and whole-of-life.

IDENTITY IN KEY NDIS FRAMEWORKS

How do key NDIS documents with legislative or regulatory obligatory functions reflect or omit identity?

- NDIS Act (2013)
- NDIS Practice Standards
- NDIS Supported Decision Making Policy
- NDIS PBS Capability Framework

In this preparatory exercise, we were careful to exclude instruments that were not broadly enforceable or auditable, eg:

- Workforce Capability Framework
- NDIA LGBTIQA+ Strategy (very small coverage)

Substantive omissions:

- **None of them use** the terms LGBT*, sexual orientation, 'gender identity', gay, lesbian, bisexual, or transgender.
- The only related terms are **sexual expression** and **diversity** - both open to broad and ambiguous interpretation. "Diversity / values / beliefs" clauses are framed around culture, faith and background, and pre-suppose participant-led engagement, meaning SOGI support can be easily overlooked for a person who has not had support for identity formation.
- Problematic gaps in PBS standards and framework. Eg. Sexuality, LGBTQ identity, gender-related distress not listed as examples of potentially unmet needs.
- Identity attributes like culture and faith are present, **but not in the framing of identity formation and self-concept.**

WHY A SCOPING REVIEW?

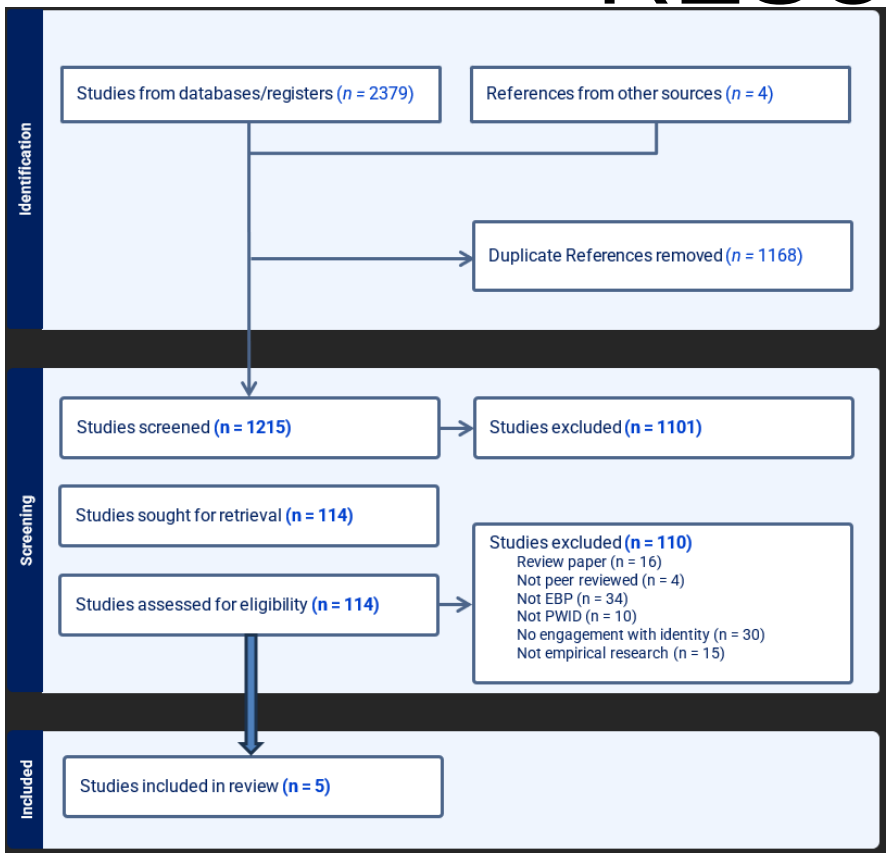
- Reviews are conducted to:
  - Summarise and synthesise existing findings within the academic literature and to identify critical gaps.
  - Explore and map themes within existing research, particularly in under-researched topic areas like LGBTQ+ identity in disability support.
  - Approach synthesis in a structured, transparent and replicable way.

- Based on our familiarity with the literature, we knew LGBTQ+ identity was going to be an underexplored area, so we expanded the scope of our search to include the word 'identity' - in line with literature relating identity to agency and personhood.

- We reviewed **primary research/empirical studies.**
  - Studies had to be about a form of **evidence-based practice** and had to **engage with some form of social identity *in addition* to intellectual disability** (e.g. **gender, sexuality**, race, culture, class).
  - Opinion pieces, theoretical work, other literature reviews were all excluded. Phenomenological research was mostly excluded, however this kind of work with LGBTQ people with intellectual has increased in the past 15 years, much of it in Australia. This work was important for initial framing and in analysis.

SEARCH PROTOCOL AND RESULTS

Search Code	Query	Results
S1	("decision making" adj2 (support* or practice*)).mp.	10,022
S2	"active support*".mp.	661
S3	"behavio?r* support*".mp.	2,034
S4	S1 or S2 or S3	12,703
S5	Persons with Intellectual Disabilities/	3,714
S6	exp Intellectual Disability/	109,764
S7	(mental* adj1 (retard* or handicap)).mp.	39,199
S8	(disab* adj3 (intellectual* or development* or learning or mental*)).mp.	129,150
S9	"development* impair*".mp.	1,200
S10	"development* delay*".mp.	23,144
S11	S5 or S6 or S7 or S8 or S9 or S10	199,266
S12	S4 and S11	299



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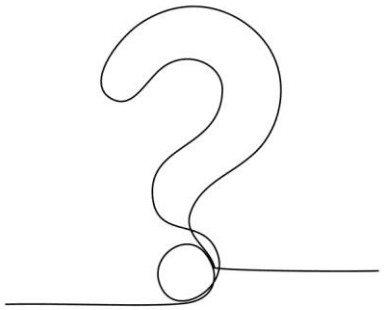
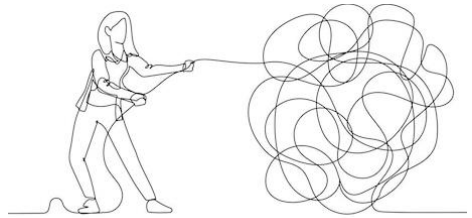
STATE OF THE RESEARCH

- Across all studies, research relating to two EBPs - Positive Behaviour Support (PBS) and Supported Decision-Making (SDM) - engaged with identity, although this was somewhat minimal.
  - Research about Person-Centred Active Support (PCAS) didn't include any discussion of identity formation and development, even though it's one of the most widely promoted frameworks for inclusion.
  - Researchers often *name* social identities like gender and race within their samples but rarely analyse how these identities shape participants' internal and external experiences or, by extension, their own perception of their support needs.
- Identity is positioned as incidental, not as the framing of the research
  - Gender and sexuality framed as *risk factors* or in relation to behaviours of concern. Little focus on the considerations like positive identity affirmation, or the protective aspects of identity.
  - Evidence-based practices were often referenced peripherally rather than used as core analytical frameworks.
- Limited engagement with the perspectives of people with intellectual disability themselves.
- Only one study (Smith et al., 2025) treated identity as *central* to self-determination and demonstrated that recognition or denial of LGBTQ+ identity directly shaped autonomy.
  - Identity isn't irrelevant — it's under-acknowledged.



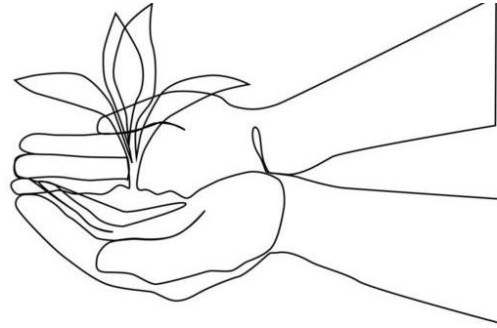
POSITIVE BEHAVIOUR SUPPORT (PBS)



- Wheeler et al., (2025), Gosden-Kaye et al. (2024), Deffew et al., (2022).
- Across all three studies, identity is engaged mainly through Behaviour Support Plans (BSPs).
  - Identity is indirect, and is inferred via behaviour / risk language / staff interpretation
- Tentative evidence of implicit bias within PBS support practices.
  - Gosden-Kaye et al., (ibid): reveals a gendered pattern – women's behaviours are framed more negatively; women with intellectual disability are monitored more closely
  - Wheeler et al., (ibid) points to racialised framings – whiteness treated as the "default"; other identities reduced to surface descriptors.
  - Deffew et al. (ibid) suggest that supporters' age, gender and religious beliefs influence their engagement with needs relating to sexuality.
    - Support workers' own identities are treated as neutral / unmarked, their own biases are un
- Even where PSB support practices were more holistically investigated (Deffew et al., ibid), sexual identity appeared only within BSPs, not in broader support planning.

SUPPORTED DECISION-MAKING

- Smith et al., (2025); Jamieson et al. (2016).
- Within both studies, Identity is positioned as central to how decision-making is supported
  - Intersecting identities (e.g., motherhood, culture, disability) shape choices and available support
- Normative assumptions present structural constraints upon autonomy and not merely capacity.
  - LGBTQ+ identities often suppressed due to organisational risk aversion (Smith et al., ibid).
  - Likewise, motherhood as a role identity constrained by normative assumptions of "unfitness" of women with an intellectual disability (Jamieson et al., ibid).
- Identity suppression is not just loss of expression, but it shifts control to support workers.
- Smith et al. (ibid) further suggests a narrow definition of risk
  - Risk framed in terms of family comfort and reputational concern, LGBTQ+ identity seen as "influence" to be prevented, rather than affirmed.
  - By contrast, risk of denying identity (e.g., isolation, loss of autonomy) are not acknowledged.
- Findings from both studies suggest that not engaging with PWIDD's social identities contradicts the core principles of supported decision making.



DISCUSSION

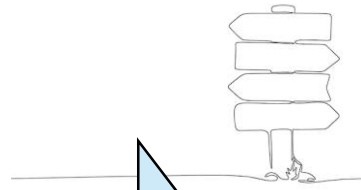
- Research on personhood, citizenship, agency, legal capacity, self-determination, identity, and even self-concept for people with intellectual disability share a common logic. (Fyson & Cromby 2013; Bach 2017; Chalachanová et al 2021)
  - Recognise importance of internal development of a person's identity in developing agency. Application of support to enable this internal development is a common secondary theme (incl. communication and SDM).
  - Share broader logic with discourse about rights and core attributes (culture, faith, sexuality, gender).
- Foundations of the core evidence-based practices - SDM, PBS and PCAS – clearly built on this same logic and conceptual evidence-base, incorporating language of agency, communication, unmet needs, etc.
- In SDM literature, autonomy is described as relational and dependent on knowing the person's self-identity and self-concept (Bigby & Douglas 2015; Arstein-Kerslake et al 2017, 2021). PBS also depends on understanding behaviour in social and relational context and on recognising unmet needs for belonging and affirmation. (Gore et al 2013; NDIS Prac Stand.s)
- However, across NDIS instruments and practice frameworks, this link breaks down. References to sexuality, gender identity and other core attributes are replaced by broad terms like "values", "culture", "beliefs" and "diversity". These often rely on self-initiated declaration/disclosure.
  - This contrasts with international and national rights frameworks that list culture, faith, gender and sexual orientation together as protected attributes.
  - These terms do not appear in the context of support for identity formation and development.
- Despite the marked difference between leg/reg instruments and EBP research, **very** similar omissions occur.

IMPLICATIONS

- Omissions in key instruments and EBP literature means there is a gap in the 'how to' of deep support for identity and rights for LGBTQ PWID, particularly for suppressed LGBTQ PWID who have not had support for initial sexual or gender dentity formation.
- Research on relationships, intimacy and self-concept shows these are core developmental needs for PWID (O'Shea & Frawley 2020; Neuman 2022).
- SDM practice often starts with 'knowing the person' and identifying key relationships, then focuses on supporting choices and promoting autonomy, but has not been formally applied in a research context to helping people do the inherent and deep exploration and testing of identity or self-concept in relation to core attributes.
- The gap is reinforced by the absence of intersectional and LGBTQ+ examples in PBS, SDM and PCAS evidence bases.

Yet:

- Hill et al (2022) show LGBTQ+ PWID experience the worst mental-health and safety outcomes in the LGBTQ+ population. The omission of SOGI support is therefore a real risk issue. (**Private Lives 3** and **Writing Themselves in 4** national surveys.)
- Reconnecting these ideas would not change the intent of EBPs. It would make them more complete, aligned with their own theoretical roots, and address the needs of one of the most marginalised cohorts.



LGBTQ and identity:

- CRPD GCs 6+7
- Australian anti-discrim and EO laws
- NDIS non-enforceable docs (WCF and NDIA LGBTIQA policy
- Intellectual disability phenomenological and rights research
- Some conceptual research about EBPs

Omission:

- Foundational NDIS instruments, laws and standards
- Applied EBP research

QUESTION TIME