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TEACH

Transforming early Education And Child Health Research Centre

Hiding in Plain Sight: Using population research to improve outcomes for mothers with intellectual disability and their children

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Acknowledgment of Country

I acknowledge that we are meeting on the traditional lands of the Gadigal people of the Eora nation and extend my respects to their Elders past and present.

I also acknowledge the Barramadigal, Tharawal, Gandangarra, and Wiradjuri peoples on whose lands the campuses of Western Sydney University stand.

Artwork created by Bradley Burns, PhD candidate, TeEACH

Background

Parents with intellectual disability invisible within general population.

Evidence from small, clinical samples (cross-sectional, qualitative studies) presents them as homogenous and through the prism of disability.

Focus of research is caregiving quality, maternal and infant health, child protection, contextual risks.

Some population studies compare parents with and without intellectual disability.

Greater risk of child protection and out-of-home care, pregnancy and postpartum health complications than *general population*

Unknown if their circumstances are similar or different to *at-risk groups*

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Background

Studies show mothers with intellectual disability fit the profile for 'at-risk' of child removal

- Young maternal age,
- Single parenthood,
- Social contexts of poverty, housing insecurity, rural location.
- Individual factors e.g. mental health, substance misuse, intimate partner violence, childhood adversity

But absent from general population research about at-risk parent populations.

Research question

What sociodemographic characteristics are most frequently reported in population-level studies about parents with intellectual disability and

What differences, if any, are there between the sociodemographic characteristics of parents with and without intellectual disability?

Sociodemographic characteristics

- Gender
- Age
- Socioeconomic status
- Ethnic or Indigenous background
- Marital/partner status
- Education level
- Employment and health status
- Household composition

Included studies

We looked at population studies published from 2003 to 2023.

- 26 eligible studies from two reviews on this topic.
- Searches of 7 databases (medical, health, social) retrieved 3583 studies. After title and abstract check, 29 studies deemed eligible
- **55 studies** were subject to full-text review, **27 met inclusion criteria**
- We extracted information about the sample size, comparison group, statistical analysis, and outcomes.

Overall findings

Focus on maternal and child health, child development and child protection.

- 100% from the Global North
- 71% North America
- 59% published between 2019 and 2023
- 67% on pregnancy and birth outcomes

Overall findings

Only 3 sociodemographic variables were recorded in <50% of studies:

- Gender – 100% (all included mothers, 1 both mothers and fathers)
- Age – 96%
- Socioeconomic status – 85%

Age and socioeconomic status

Age indicators:
4 studies calculated means, 17 provided age range, and 5 reported both.

19 of 26 studies (73%) reported statistically significant difference:
mothers with ID were younger than those without.

Socioeconomic status indicators:
income or housing; insurance type (private/public/uninsured), low assets, unemployment, neighbourhood adversity/social capital.

18 of the 23 studies (78%) reported statistically significant difference:
mothers with ID more disadvantaged than those without.

Finding 1:

Mothers with intellectual disability and their children fall within identified at-risk parent groups in the general population

They are invisible in population-level datasets about parent/child groups.

Implications

Disability researchers need to put this issue on the agenda of national statistical offices and then work with them to include standard data items about disability and disability group as well as relevant parenting and child outcome items.

Finding 2:

Marital or partner status was not consistently available and fathers with intellectual disability are invisible

Implications

Disability (maternal) is seen as a determining factor in risks and outcomes

It is not possible to determine if single motherhood poses a parenting risk.

Need to define father status (biological parent, male partner in parenting role)

Finding 3:

We don’t know whether any of these characteristics are more likely among parents with intellectual disability than other at- risk parent groups

General parenting literature shows risk factors are cumulative, co- occurring

Implications

Need to have the information for multi-factoral analysis of nuanced relationship between disability, young parenthood, poverty (& other sociodemographic factors) and poorer child outcomes.

Next steps for research

Population-level studies extract *more variables about parents* from available datasets to flesh out the picture more fully.

Mixed methods research *to understand why* girls and young women with intellectual disability are significantly more likely to become parents earlier.

Life course research with young mothers with intellectual disability and those who became mothers at a young age *to understand journey to parenthood* and decision-making influences.

Co-design *mapping of health/social care services* for new [& young] mothers with intellectual disability to improve antenatal and early infant care services for these mothers and babies.

Next steps for policy and practice

Governments responsible for addressing disparities in child outcomes need to align policies to ensure:

- accessible sexual health literacy so girls and young women with intellectual disability can make informed choices about parenthood
- accessible maternal and child health programs and information, including programs specifically for young mothers
- universal design principles incorporated into all mainstream parenting and family support programs

Governments responsible for Australian population data and administrative datasets to capture disability items and record parenting demographics

THANK YOU

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