

HEALTH AND SOCIAL POLICIES FOR AUSTRALIAN MEN AND BOYS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITY: A HEALTH AND WELLBEING DOUBLE JEOPARDY?

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Intellectual disability is characterized by a combination of limitations in *intellectual functioning* and *adaptive behaviour* originating during the developmental period, before the age of 18.¹ Intellectual functioning refers to an individual's capacity to learn, problem solve and reason; adaptive behaviour refers to the conceptual (e.g., language, money, time), social (e.g., interpersonal skills, social responsibility, ability to follow rules), and practical (e.g., personal care, travel, use of telephone) skills. Developmental disability is a term used to describe lifelong physical and/or cognitive disabilities and includes, but is not limited to, intellectual disability, cerebral palsy, autism, Down syndrome, Attention Deficit Hyperactivity Disorder (ADHD; in the USA) and fetal alcohol syndrome.² As intellectual and developmental disabilities often co-occur, most health, educational and social professionals work with people who have both.

The prevalence of intellectual and developmental disability differs significantly depending on the terms used and data sourced. For example, a meta-analysis of population-based studies reported a prevalence of intellectual disability at about 1% of the population.³ Yet, the most recent prevalence report by the Australian Institute of Health and Welfare (AIHW)⁴ reports that 3% of the population has intellectual disability. If we expand this to a focus on diagnosis of developmental disability, US data suggests a prevalence of developmental disability of 13.87%,⁵ however this includes a diagnosis of ADHD and other learning disorders (e.g.,

dyslexia) which are usually not always considered a developmental disability outside of the USA. Part of the reason for such a discrepancy is due to the lack of a standardized intellectual and developmental disability identifier and population datasets often using proxy reporting without any direct assessment of individuals.⁶

What does not differ however, is the greater overall ratio of males to females with intellectual and developmental disabilities. For example Maulik et al. report a female to male ratio between 0.7 and 0.9 in children/ adolescents between 0.4 and 1.0 in adults.³ Boyle et al. report that boys have twice the prevalence of all types of developmental disability with a significantly a greater prevalence of autism.⁵ Despite these males with intellectual and developmental disability being the largest disability group, by gender, in Australia,⁷ and numbering more than several other marginalized male sub-groups, they and their health needs are not specifically mentioned in the National Male Health Policy.⁸ Rather, the policy refers on a few occasions to "males with disabilities" which includes older men with acquired disabilities and other disabilities that do not have a comparable impact on social and economic participation over the lifespan. Further, the policy document specifically names and argues that a range of other very specific male sub-groups warrant specific health promotion strategies in relation to the health and wellbeing disparities they face. Yet, when compared to men and boys in the general population,

the health and wellbeing of men and boys with intellectual and developmental disability is significantly poorer and they experience greater exposure to the social determinants of poor health.⁹

Although intellectual and developmental disability is not a male-specific issue, there clearly warrants a focus on their health and wellbeing, yet there is a dearth of international and Australian research outlining a male health agenda *or* meaningful data about men and boys with intellectual and developmental disability.¹⁰ Disappointingly, although the Australian National Male Health Policy was published in 2010, there is little evidence of policy change or practice demonstrating that it has had any impact on the lives of men and boys with intellectual and developmental disability in Australia.¹¹ Moreover, evidence of the Australian Male Health Policy making its impact into or mention within disability policies is likewise missing. As Misan argued, the lack of a clear understanding of *how* male health policies are meant to interconnect with other health and social policies, remains unclear.¹² Australia is embarking on an individualized policy approach to the provision of disability supports and services – the National Disability Insurance Scheme (NDIS) – and at this stage the only focus on gender-specific issues relate to issues of abuse and the heightened vulnerability of women with disabilities to exploitation, violence and abuse.¹³ This focus also extends to the Australian funded research program into women’s safety where a program of research has provided policy and practice recommendations for better access to family violence services for women with disabilities.¹⁴

In the absence of a presence of intellectual and developmental disability in male health policy or of male health in disability policy, our intention in this article was to start to address this gap by describing what the literature does tell us about the health and wellbeing of men and boys with intellectual and developmental disability and to make some recommendations for research, policy and practice. It is not a conventional review consisting of a description of results/findings nor does it provide a critique of research quality. One of the main barriers to conducting such a conventional review is the, too often, de-gendering of people with intellectual and developmental disability in the published literature,¹⁵ making meaningful analysis of

gender-specific health data often impossible. Rather, we wanted to describe the primary topic areas of focus and to start a discussion about a more robust male health agenda for men and boys with intellectual and developmental disability.

METHODS

The two concepts of interest for the review were intellectual and developmental disability and male health. The search terms used were: men’s health OR male health OR male wellbeing AND intellectual disability* OR intellectual impairment* OR cognitive disability* OR mental* retard* OR mental* deficient* OR mental* defective* OR learning disorder* OR learning disability* OR developmental disability* OR mentally Disabled Person*. A systemic search was conducted of six databases: Medline, CINAHL, Web of Science, Embase, PsychInfo and Cochrane. The results from all databases were saved as an Endnote file which was cut down further and categorized into sub-groups. Searches were made of titles, abstracts and key words. Our exclusion criteria were articles containing any terms relating to women’s health, maternal or natal, autism, genes, or psychiatric disability. Of the 1518 articles identified, all authors worked together over a period of 3 months to screen articles and based on titles and abstracts, 29 were removed as duplicates, 38 were removed as miscellaneous/irrelevant, and 751 were excluded from the database based on the stated exclusion criteria. We then removed all articles published prior to 1995, those without a published abstract, papers that described genetic features without any actual participants, and those which were about both men and women with intellectual disability leaving us with a final list of 53 articles that were based on males with intellectual and developmental disability.

RESULTS

Table 1 provides a descriptive summary of our results categorized into 24 topic sub-groups together with a statement about the design, the sample size and country of origin. Although there are a range of health and wellbeing topics covered, our results are not illustrative of an advanced body of male health research for men and boys with intellectual and

TABLE 1 Description of Review Results

Topic area	Number of Papers	Paper	Design	Size	Country
Abuse	1	25	Survey of staff	20-100	UK
Cancer	3	53	Opinion Paper	NA	UK
		43	Case study	Single	France
		18	Opinion Paper	NA	UK
Challenging Behaviour	3	10	Experimental	20-100	Spain
		29	Experimental	5-20	Ireland
		12	Experimental	5-20	UK
Description of Syndrome	12	26	Experimental	20-100	USA
		24	Experimental	Not specified	USA
		1	Case study	<5	USA
		8	Case study	<5	USA
		34	Systematic Review	NA	Spain
		45	Systematic Review	MA	Denmark
		27	Case Study	<5	Turkey
		44	Retrospective Data analysis	100-500	UK
		19	Prevalence Study	20,000+	Egypt
		4	Case study	<5	USA
		41	Opinion Paper with case examples	MA	Canada
Dental	3	43	Case study	Single	France
		5	Unspecified	Unspecified	Nigeria
		31	Opinion Paper	Single Participant	USA
Criminal Justice	2	16	Experimental	100-500	Canada
		38	Retrospective Data analysis	2000+	Canada
Fitness and Exercise	7	11	Experimental	20-100	Spain
		28	Experimental	5-20	Portugal
		47	Experimental	5-20	Ireland
		15	Experimental	20-100	Spain
		3	Experimental	5-20	Finland
		32	RCT	20-100	Tehran
Dual Diagnosis	1	22	Experimental	20-100	Turkey
		33	Demographic description	8000+	Canada

Continued

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Topic area	Number of Papers	Paper	Design	Size	Country
Gender Dysphoria	1	13	Retrospective Data analysis	5-20	UK
HIV/AIDS Prevention	1	51	Experimental	20-100	US
Diabetic Management	1	50	Case study	<5	Australia
Mental Health/Psychiatric Inpatient	3	52	Qualitative analysis	5-20	UK
		17	Qualitative analysis	5-20	UK
		39	Retrospective Data analysis	100-500	UK
		38	Retrospective Data analysis	2000+	Canada
Penile Hygiene	1	30	Staff Survey	20-100 staff	UK
Addiction treatment (substance abuse/tobacco)	3	14	Staff Survey	20-100	Northern Ireland
		37	Case study	Single	USA
		49	Experimental	<5	USA
Relocation to Community	1	10	Experimental	5-20	UK
Sexually Abusive or Offending Behavior & Treatment	6	17	Experimental	5-20	UK
		29	Staff Survey	20-100	UK
		2	Staff Survey	Unspecified	UK
		20	Qualitative Analysis	5-20	UK
		21	Qualitative Analysis	5-20	UK
		23	Experimental	20-100	Canada
Sexual Health/Sexuality	6	35	Qualitative Analysis	5-20	Australia
		40	Opinion Paper	NA	Australia
		36	Opinion Paper	NA	Australia
		48	Opinion Paper	NA	Australia
		41	Opinion Paper	NA	Canada
		23	Experimental	20-100	Canada
Sterilization	1	6	Qualitative Analysis	20-100	Australia
Testosterone Deficiency	1	7	Opinion Paper	NA	Australia
Testicular Self-Examination	1	18	Opinion Paper	NA	UK
Undescended Testes	1	42	Staff Survey	100-500	Austria
Mindfulness	2	37	Case study	Single	USA
		49	Experimental	>5	USA
Musical Engagement	1	46	Case study	Single	Australia
Seizure Management	1	44	Systematic Review	NA	NA
Staff Attitudes	1	30	Experimental	20-100	Australia

developmental disability. The country publishing the largest body of the work is the UK ($n=18$), followed by the USA ($n=11$), Australia ($n=9$) and Canada ($n=8$). Experimental studies (whether RCT, pseudo-RCT, quasi-experimental, or pre-post) were the largest study design ($n=20$) followed by case studies ($n=11$) and opinion pieces ($n=10$). The bulk of the experimental studies were about physical activity and exercise and interventions for challenging behaviour. There was only one systematic review of the literature and this was about seizure management for people with Lennox-Gastaut syndrome, a disorder more common in males than females.¹⁶

The largest topic sub-group – description of syndrome ($n=12$) – simply defines and describes a range of syndromes/disorders which is not surprising given the increased prevalence of males with x-linked disorders such as Fragile-X, Down syndrome and autism. Table 2 provides a breakdown of all the syndromes/disorders described in this topic sub-group plus others ($n=3$) that appeared in other topic sub-groups. The second largest topic sub-group was fitness and exercise ($n=7$) and all of these studies had experimental designs, some with relatively large sample sizes. The next largest topic sub-groups were about sexual offending ($n=6$) and sexual health ($n=6$). The majority of the research on sexual offending was based in the UK and was mostly descriptive in nature with the majority of research about sexual health being based in Australia and was mostly opinions and perspectives. Although there was some research focus on testicular cancer ($n=2$), penile hygiene ($n=1$), testicular self-examination ($n=1$), undescended testes ($n=1$), hypogonadism ($n=1$), and sterilization ($n=1$), these were all descriptive, qualitative or opinion pieces. There was a total absence of any research about screening for prostate cancer.

DISCUSSION

This paper is one of the first to start to seriously conceptualize what literature exists that is about men and boys with intellectual and developmental disability in an attempt to start a narrative about developing a robust men’s health agenda. Our broad conclusion is that the body of research specifically about the health and wellbeing of men and boys with intellectual and developmental disability is very limited with a

TABLE 2 Specific Syndromes

Syndrome	Number of papers	Paper #
Down Syndrome	4	11
		28
		15
		53
ASD	2	39
		9
Fragile X	4	24
		34
		19
		26
Klinefelter	1	45
Seckel	1	27
Rett	1	4
Lennox-Gastaut	1	44
van den Ende-Gupta	1	8

patchy coverage of topic areas. Most notable was the absence of health promotion research about testicular and prostate screening, heart disease, hypertension and diabetes. Given that Australia is an international leader in having a well-developed male health policy, the relatively small body of Australian research about men and boys with intellectual and developmental disability is somewhat surprising, although the time taken to conceptualise research, conduct a study and have it published means the impact of the male health policy may yet be some time away. Although there were a number of experimental studies, there were also a large number of case studies and opinion pieces which, while useful in their own right, do not offer the same rigour that is required to answer the call of the National Male Health Policy to build the evidence base.⁸

We are acutely aware of an under-reporting of gender and/or sex differences in the disability literature where disability researchers do not always report gendered disparities.¹⁷ That is, research that totally de-genders the person by only referring to gender-neutral “participants”, or research that fails to report sex differences.¹⁵ This degendering of people with intellectual and developmental disability has been unpacked in more detail by Wilson, Parmenter, Stancliffe, Shuttleworth and Parker where they reported that what had been published about men and boys generally had a pathological focus – research about males as problems.²⁷ By contrast a significantly different ($p < .01$) research and practice agenda was noted about women and girls with intellectual and developmental disability where the health and wellbeing research covered topics such as menstrual support, breast screening, cervical screening, menopause, osteoporosis, contraception, and women’s health promotion activities. In fact, the leading international association about research and people with intellectual and developmental disability – *The International Association for the Scientific Study of Intellectual and Developmental Disabilities* (IASSIDD) – has published health guidelines that include a section on women’s health, but nothing on men’s health.¹⁸ In addition, an excellent and recent publication about health promotion for people with intellectual and developmental disability has no section on health promotion and gender, but does briefly describe a breast screening and women’s health curriculum in a chapter about cancer.²⁵ There are two core problems here that need to be rectified: (1) reducing people with intellectual and developmental disability (whether male or female) to a gender-neutral “other”, and (2) the absence of a more advanced research agenda about male health.

RECOMMENDATIONS

1. Disability researchers need to engage more with mainstream male health researchers, policies, and initiatives. Whether disability researchers tend to operate in a bit of a silo remains open to conjecture, but evidence of any kind of engagement with male health policies appears non-existent. This is a particularly acute problem in countries such as Australia that has a formal male health policy based on the social determinants of health and tackling inequality; a major theme in research about disability and health.²⁰
2. Although there are some problems identifying all people with intellectual disability in population surveys, despite a straightforward international definition,¹ researchers need to improve their data collection and reporting by using a standard disability identifier *and* reporting of gender at all times. For example, excellent research about attachment between people with ID (69% sample male) and caregivers (majority female) is hampered by virtually no discussion of gender.²¹
3. A range of practice specific initiatives need to be developed that brings together health workers, people with intellectual and developmental disability, families, and paid caregivers. These include, but are not limited to, initiatives about prostate and testicular screening, training nominated paid caregivers to take on a specific male health promotion role, expanding the role of the nurse practitioner to include expertise on intellectual and developmental disability, and better connections with mainstream men’s health services (where they exist).
4. One challenge for countries such as Australia, however, where disability nursing is no longer a recognized separate classification as it is in the UK and Ireland, is strategies to better train generalist nurses in how to communicate and work with people with intellectual and developmental disability.²² Generalist nurses who have this training and experience are therefore better placed to support paid carers in implementing the practice specific initiatives in recommendation 3.²³
5. There needs to be more intervention-based research and less opinion/perspectives and case studies in order to truly build the evidence base. The Centre for Disability Research and Policy recently conducted an audit of all disability research in Australia concluding that far too much research described problems and too little research actually seeks to solve these problems.²⁴ There are some examples of disability researchers taking and adapting mainstream health interventions to

improve the health and wellbeing of people with intellectual and developmental disability. One great example is the current work of Taggart, Coates, Clarke, Truesdale-Kennedy & Bunting where they are adapting a mainstream type 2 diabetes program to suit adults with intellectual and developmental disability.¹⁹ This approach needs to be taken to address male health inequalities such as for prostate and testicular screening. In another recent Australian paper, Trollor, Salomon, Curtis, Watkins, Rosenbaum, Samaras & Ward provide an excellent resource for general practitioners to help them confidently improve the cardiometabolic health of adults with intellectual disability.²⁶ Their framework is de-gendered and does not include specific strategies for working with men with disabilities despite the increased risk to males reported by the Australian National Male Health Policy for coronary heart disease.

LIMITATIONS

As this was a scoping review we only analyzed titles and abstracts; a more comprehensive analysis of manuscripts would likely yield a deeper insight, however the clear gaps in the literature are quite obvious. Due to the large number of included studies, we have not supplied a full reference list for Table 1; a full reference list of all manuscripts included in Table 1 are available from the first author upon request. The under-reporting of gender and sex differences by researchers limits the capacity to truly come to grips with the wider body of work – whatever does exist – about male health and intellectual and developmental disability. We assume that there is some data reporting on sex differences that would add to the value of this review, however while these data remain buried within the body of many manuscripts, they are inaccessible in a descriptive scoping review such as this.

CONCLUSION

There are clear and obvious health inequalities that people with intellectual disability face when compared to the general population.²⁰ For men and boys with intellectual and developmental disability, they face a double jeopardy due to their disability and the dearth of research outlining a male health agenda *or*

meaningful data about them.¹⁰ This review only further highlights the extent of the issue as we have outlined an, at best, sketchy body of male health research for this substantial sub-group. The Australian National Male Health Policy calls for researchers to develop the evidence base,⁸ yet there is not enough experimental or evaluation research to effectively do this. This is a bit of a wake-up call in many ways for us as Australian disability researchers as all we have done here is described a gap; we have not solved a problem. The current generation of disability researchers must harness the potential of mainstream health policies to better provide an established evidence base for the next generation of researchers to develop. The risk of not doing this will be more description and too little solving of problems.

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