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Research Paper

# An exploration of an ethics of care in relation to people with intellectual disability and their family caregivers in the Cape Town metropole in South Africa



*Une exploration de l'éthique du care pour les personnes avec un handicap mental et leurs pourvoyeurs familiaux de care dans la ville du Cap en Afrique du Sud*

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## ARTICLE INFO

### Article history:

Received 6 March 2014

Accepted 30 November 2015

Available online 12 January 2016

### Keywords:

Intellectual disability

Ethics of care

Family carers

Western Cape

## ABSTRACT

People with intellectual disability (ID) are defined as a group by their need for lifelong support. For the most part, it falls to family caregivers to provide this support. This paper begins with a critique of a human rights perspective in dealing with family care and argues for an ethics of care in understanding the support needs for families and adults with ID. This perspective is then applied to a study that was undertaken in 2013 in the Cape Town metropole in the Western Cape Province of South Africa on the views of people with ID and their families on meeting care needs in this context. Sixteen adults with ID and 38 family caregivers were interviewed and the data was analyzed by means of a thematic analysis. The themes that emerged were: (a) the need for “another mother”, (b) protection from crime, violence and abuse, (c) maximizing independence, (d) accessing resources and (e) community integration. These themes

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are discussed in the light of an ethics of care, using Tronto's (1993) elements of care as an analytic tool to explore how care needs might be thought of in the study context.

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## R É S U M É

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### Mots clés :

Handicap mental  
Éthique du care  
Pourvoyeurs familiaux de care  
Province Ouest du Cap

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Les personnes avec un handicap mental sont définies comme un groupe du fait de leur besoin de soutien tout au long de la vie. Pour la plupart d'entre elles, il revient à la famille de fournir ce soutien. Cet article commence par une critique de l'approche en termes de droits humains en étudiant le care des familles ; il défend l'usage d'une éthique du care pour favoriser la compréhension des besoins de soutien à apporter aux familles et aux personnes handicapées. Cette approche est appliquée à une recherche menée en 2003 dans la ville du Cap (Province de Cap Ouest) en Afrique du Sud auprès de 16 personnes avec un handicap mental et de 38 pourvoyeurs familiaux de care. Les thèmes qui ressortent de cette recherche sont les suivants : (a) le besoin d'une « autre mère », (b) le besoin de protection du crime, des violences et des abus, (c) la recherche d'une maximisation de l'indépendance, (d) l'accès aux ressources et (e) l'intégration dans la communauté. Ces thèmes ont été discutés à la lumière de l'éthique du care, utilisant l'analyse de Tronto pour explorer la façon dont les besoins de care doivent être rapportés au contexte étudié.

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Intellectual disability is defined by limitations in intelligence and adaptive behavior that can be ameliorated through appropriate individualized supports (American Association on Intellectual and Developmental Disabilities, 2008). This implies that people with intellectual disability (ID) will require ongoing lifelong support (to a greater or lesser extent depending on the severity of the impairment) in a condition of “inevitable” dependency (Kittay, Jennings, & Wasunna, 2005). Regardless of what education and training for independence they might receive as children, they are most likely to require supported living and working environments as adults. While in many developed countries this kind of support may be partially provided through formal caregiving services by the state, it remains the case that the majority of adults with ID, in both developing and developed countries, are cared for by their families, in a multitude of forms and structures (Braddock, Emerson, Felce, & Stancliffe, 2001; McKenzie, McConkey & Adnams, 2013a). The current paper explores the interdependent relationships between family caregivers and adults with ID living in the Cape Town metropole. I shall begin by presenting a brief discussion of the application of human rights and explore the potential of an ethics of care to complement these claims to rights and examine how this might be done before presenting a study on caregivers and individuals with ID carried out in the Western Cape, South Africa. The conclusion to this paper will present some suggestions as to how we can draw on an ethics of care to understand and meet the care needs of people with ID and their families.

## 1. Social justice, rights and intellectual disability

The social model of disability views the marginalization of disabled people as an issue of social justice rather than a product of individual impairment. People with disabilities are consistently excluded from the fair distribution of goods in society by virtue of their perceived incompetence arising from

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