Health conditions and support needs of persons living in residential facilities for adults with intellectual disability in Western Cape Province

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Background. Intellectual disability (ID) is a relatively high-incidence disability, with an increased risk of poor physical and mental health. Persons with ID also have lifelong support needs that must be met if they are to achieve an acceptable quality of life. Little is known about these health conditions and support needs in the African context. This study examines persons over the age of 18 years with ID in residential facilities in Western Cape Province.

Objective. To analyse the health conditions and support needs of persons with ID in Western Cape Province.

Method. A survey of residents' health conditions and support needs was conducted in face-to-face interviews with the managers of 37 out of 41 identified facilities.

Results and conclusion. The survey comprised 2 098 residents (54% of them female), representing less than 2% of the estimated population of persons with ID in the province. The survey suggests that such persons experience a wide range of health conditions (notably mental health and behavioural issues) but have limited access to general healthcare and rehabilitation services. Furthermore, the daily living supports required for an acceptable quality of life are limited. The findings highlight the need for better health and support provision to persons with ID.

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The health conditions and support needs of persons with intellectual disability ((ID); i.e. impaired cognitive and adaptive functioning present from birth or soon after[1]) in their adult years is a neglected subject in the African context, despite international evidence that these individuals are at greater risk of poor physical and mental health than the general population.[2,3] This increased risk is exacerbated by the reduced ability of such persons to communicate their needs.[3] Furthermore, their wellbeing is diminished by isolation, stigma and limited support provision, particularly on the African continent.[2]

The prevalence of ID in South Africa (SA) remains unclear. Adnams[2] cites a range of SA studies with estimates ranging from 0.27 % to 3.6% of the population having ID. This figure can be compared with that of 1.2% for the USA and 1.29% for Australia.[2] Researchers in the field note that the prevalence of ID is likely to be higher and more debilitating in Africa owing to the effects of poverty and poor nutrition as well as lack of appropriate services.[2,3] In the Western Cape (WC), Kleintjes *et al.*[4] estimated an ID prevalence of 3.05%, of which 2.5% is mild ID, 0.4% moderate and 0.15% profound. Extrapolating the prevalence figure of 3.05% to the population of the WC (reported by Statistics South Africa[5] to be 5 287 863 in 2011) suggests that there are 161 279 individuals with ID in the WC of whom 108 034 are ≥18 years old. This population is the focus of the current study. It appears that the great majority of these adult persons live in community settings, with most in family care. Smaller numbers live away from family members in some form of residential setting. There is a paucity of available information concerning the needs of this group of persons with ID, particularly in regard to their health and wellbeing. Such data would assist with plans for developing services to meet these persons' particular needs.

Objective

Our aim was to analyse the health conditions and support needs of adult persons with ID living in residential facilities provided by non-governmental organisations (NGOs) in the WC.

Methods

Residential facilities serving adults with ID were identified from existing databases maintained by the Western Cape Forum for Intellectual Disability and the Western Cape Government's Department of Social Development. Facilities were included if their primary purpose was to accommodate individuals >18 years old with ID. Those solely catering for the aged (without ID), for other types of disability or for children with ID were excluded. As the survey progressed, respondents were asked to identify other facilities known to them to ensure comprehensive coverage of all known facilities in the WC. Data presented here were ultimately based on a sample of 37 facilities.

The facility managers were contacted telephonically and informed about the aims and methods of the study. A survey questionnaire was developed, drawing on the literature and with input from various consultants to the project. It was piloted by two people experienced in working with residential facilities for people with ID, and changes were made according to their input. Facility managers were then asked to complete the questionnaire or to delegate this task to a nominee. The respondent signed a letter consenting to participation in the study. No harm to an individual could result from participation in this research. No personal data on individual residents were collected. Most respondents (35) preferred face-to-face interviews.

The information from the survey reported in this paper includes: demographic details of residents, health conditions of residents, access to healthcare and support, residents' support needs, and access to support so that they might participate in the community. Data gathering took place from November 2011 to March 2012. The data were analysed quantitatively using Statistica after appropriate checks for data coding and follow-up where necessary. Approval for the study was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC ref: 429/2011). The study adhered to the ethical principles in the Declaration of Helsinki.[6]

Results

Of the 37 facilities, 19 were in suburban areas, 10 in rural areas and 8 in high-density/township areas. Two-thirds of facilities (*n*=25) provided more than one type of care setting. Twenty-five facilities described themselves as residential centres, 19 as group homes, 15 stated that they provided special care facilities, and 3 were described as rehabilitation facilities. They had been functioning for a median of 20 years with a range of 2 - 130 years. The number of residents varied from 4 to 301, with a median of 49. More than 800 staff, of whom 90% were female, were employed in these facilities; 57% as care workers (mostly fulltime); 20% as domestics (mostly part-time) and 23% in administration and management (mostly fulltime). Of the workforce, 60% were coloured, 26% black and 15% white; this identification of the racial composition of staff and residents is deemed relevant owing to the historically disproportional provision of services. The estimated cost of running each of these facilities in the past year ranged from R150 000 to R7 million, with an average cost of R2 643 323 per facility (median R2 200 000).

Demographic details of residents

A total of 2 098 residents were in the 37 facilities (968 male and 1 130 female (46% and 54% respectively). Four facilities catered for 98 women only. The highest proportion of residents was aged between 36 and 59 years (*n*=919; 48%), and followed by 19 to 35-year-olds (*n*=567; 29%). A total of 391 persons (20%) were ≥60 years old; 57 (3%) were <19 years old. Two-thirds (*n*=1 377) of all residents were white; 28% (*n*=594) were coloured and 6% (*n*=124) were black.

Most facilities reported that they provided care across the ID range of severity. Of the 37 facilities, 22 included care provision for people with severe ID, 29 for moderate, and 28 for mild ID. Twelve facilities excluded admission of elderly persons or those with mental health problems.

Health conditions of residents

The most common support requirements for residents' health concerned the use of medications and mental health and behavioural problems (Fig. 1). Managers in 33 (89%) facilities indicated that the majority of their residents had medication needs; 22 (59%) facilities reported mental health needs, while behavioural issues were evident for almost all the residents in 18 (49%) facilities. Seventeen (46%) facilities reported mobility problems on the part of their residents. Sixteen (43%) facilities cited physical health needs in most residents. Epilepsy affected at least some residents in 84% of facilities. Sensory conditions and autism spectrum disorder respectively were reported in some residents in 23 and 25 facilities.

Access to healthcare and rehabilitation

Fig. 2 summarises access of the facilities to healthcare. Specialised nursing care was available on a daily or weekly basis in 16 (38%) facilities. Occupational therapy and medical and physiotherapy services were available, although less than a third of facilities had access on either a daily or weekly basis. While speech and language therapy,

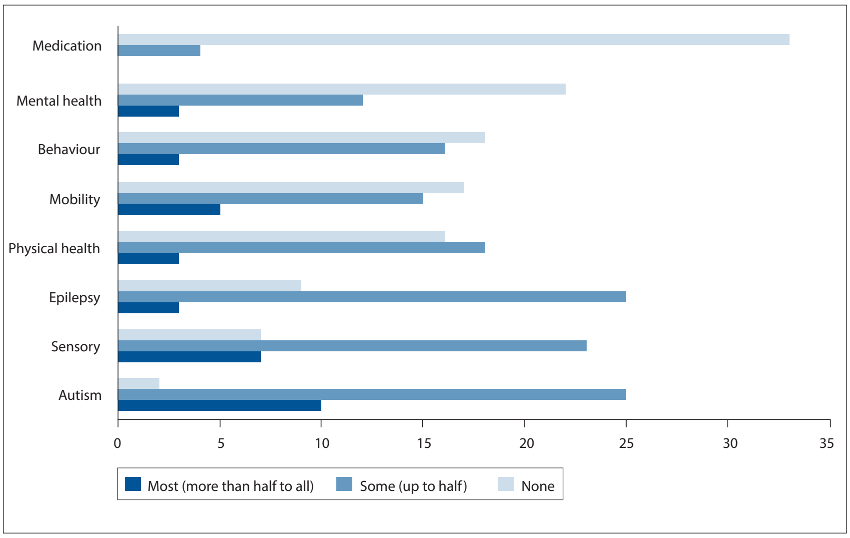

Fig. 1. Health needs of residents per facility requiring support for health conditions.

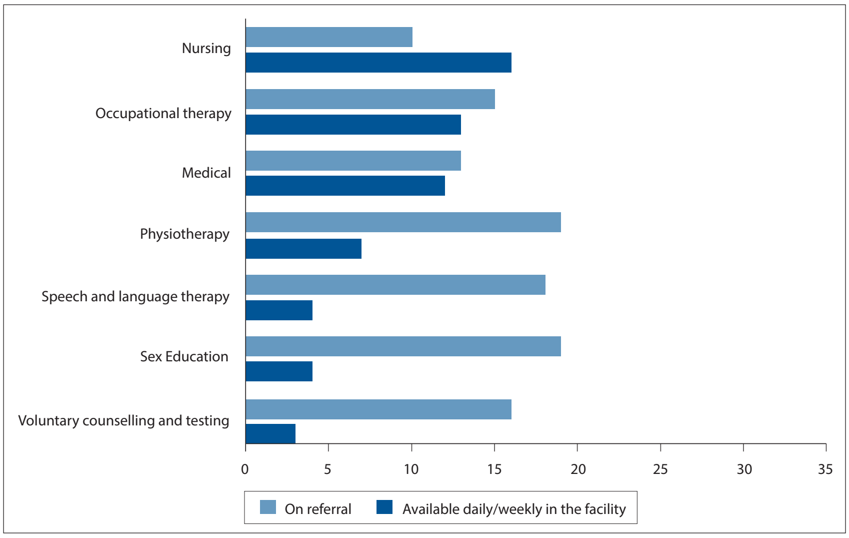

Fig. 2. Number of facilities accessing health services on a daily/weekly basis within facilities compared with access by referral.

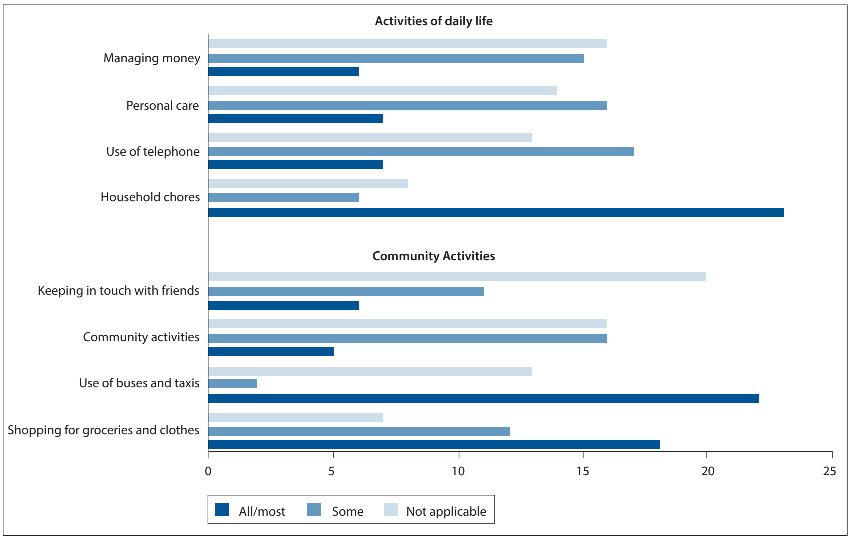

Fig. 3. The number of facilities (N=*37) reporting support needs for residents in terms of activities for daily life and participation in community activities.*

sex education and voluntary counseling and testing (VCT) for HIV/AIDS were available in a minority of facilities on a daily or weekly basis, most relied on referring their residents to other health service facilities for these and other services, as shown in Fig. 2.

Residents' support needs

The support needs of residents in conducting their lives are presented in 2 different categories: support for activities of daily living, and support for participating in community activities (Fig. 3).

In nearly all facilities, some residents required support in managing money, personal care and use of the telephone; residents were not expected to contribute to household chores; residents were not expected to use public transport such as buses or taxis, nor to shop for groceries or clothes. Most facilities offered residents support in keeping in touch with friends and participating in a range of community activities. Sixty-two per cent of facilities reported that most of their residents needed help in communicating with others.

Access to support for participating in community life

Information was gathered on indicators relating to advocacy, employment and sexual relations. Residents in 8 facilities (22% of total) had access to advocacy support at least monthly, while in another 15 (41%) facilities, individuals could be referred. However, in 14 (38%) facilities, such support was unavailable.

Most residents usually spent their days in their residences. In 8 (22%) facilities, vocational training was available on a daily or weekly basis. In only 4 (11%) facilities, were some of the residents engaged in paid or unpaid employment outside the facility. In 1 (0.2%) facility, some residents attended an outside day centre.

Sexual activity was permitted in 10 (27%) facilities under certain conditions, i.e. for married couples, with parental consent, if residents were in a stable relationship, or if they had undergone sex education. The facilities that forbade sexual relationships did not address any sexuality issues. Some facility managers expressed the view that any sexual activity for people with ID was immoral, or that their residents were not capable of having such relationships. Concern was also expressed about preventing 'abnormal' sexual practices such as masturbation and homosexuality.

Discussion

Residential facilities in the WC currently accommodate around 2 000 residents, representing less than 2% of the estimated adult population with ID in this province. This proportion of people living away from their families is much lower than in most First-world countries,[7] and is likely to be higher for white and coloured than for black residents. Facilities covered a wide range of needs in terms of levels of ID and in comorbidity, in that mobility problems and sensory impairments were reported as affecting at least some residents in most facilities.

There was a slight over-representation of females in the residential populations, according to the provincial gender figures of 49% male and 51% female,[1] and was markedly different from the male dominance (60%) of people with ID reported internationally.[2] Possible reasons for the female predominance include the existence of women-only residences, and the perceived need for protection of women with ID and their vulnerable status in SA society.

Very high levels of need for medication and high rates of mental health and behavioural problems were identified. Physical and mental health and behavioural issues probably all contributed to the high medication needs of residents, but the proportion arising from each health condition was not clear. This lack of clarity reflects an international trend where there is a generally high rate of medication, and especially of psychotropic medication, in people with ID. This rate exceeds the expected prevalence of psychoses in this population, with an association between such medication and challenging behaviours in children and adults with ID.[8] Additionally, the population with autism spectrum disorder, in which there is a 40 - 55% co-morbidity with ID,[9] tends to be highly medicated with psychotropic drugs. Given the high prevalence of epilepsy in people with ID, it could be anticipated that many of the residents in this study would have been receiving anti-epileptic medication.

Our survey reveals that facilities have limited access to general healthcare services for the health needs identified and shown in Fig. 1. Nursing, occupational therapy and medical services were the most commonly available on a weekly basis but, even then, for less than 50% of the facilities. Most services relied on referring residents for physiotherapy and speech and language therapy because these and other health services were not available in their locality or were not affordable if sought privately. This situation emphasises the requirement for an informed, comprehensive health system at the primary level of care that addresses and supports the many unmet needs of people with ID. Despite the greater vulnerability of people with ID to mental illness than among the general population,[10] there was little evidence that facilities had access to provision of mental healthcare by mental healthcare nurses, psychiatrists or psychologists. This fact no doubt relates in part to the pervasive lack of mental health services at the primary healthcare level throughout SA.[11] Residents' full health needs cannot be addressed by staff in most facilities since most staff members are employed as care assistants and domestic workers. Greater in-service training is needed for such staff; although available from local mental health agencies and universities, such training reaches only a minority of the workforce. People in SA with ID, as is the case internationally, are subject to a ‘cascade of health disparities’, as described in a recent review article.[12] This cascade ‘include[s] a higher prevalence of associated conditions, inadequate attention to care needs by caregivers, inadequate focus on health promotion, and inadequate access to quality healthcare services’.

The residential facilities surveyed appeared to place little emphasis on developing their residents’ competence and improving their quality of life. For example, residents were not expected to undertake housekeeping chores, nor to integrate with the community. Although it might be assumed that they are incapable of doing so because of their impairment, this assumption does not correlate with the finding that most facilities cater for a range of severity of residents’ impairments from severe to mild. It would be expected that more capable residents be provided opportunities to attain greater independence.

Access to support for advocacy, community participation and citizenship was limited, but emerging. Some facilities showed awareness around sexuality issues, possibly as a result of formal carer training on sexuality issues, but many ignored this seemingly awkward issue. It is imperative to address sexuality, both in terms of protection from abuse as well as enabling people with ID to experience and enjoy intimacy.

The neglect of employment and vocational training was worrying. The overwhelming majority of facilities offered no prospect of working in the open labour market or of developing residents’ marketable skills. This shortcoming is contrary to international trends that favour supported employment directed toward increased social inclusion, skills development and income generation.[13] Moreover, residents are denied the opportunity of living more independently – an option that is proving to conduce to a better quality of life and the promotion of human rights in people with ID in more affluent countries.[14] Community-based supports are needed that develop the competencies of children and young people with ID so that they can earn a livelihood and be supported in small-scale housing options or with alternative families. While there is a need for specialised residential facilities for persons with more severe ID, our survey points to an over-provision of such facilities in the absence of alternative options.

Looking ahead, the needs of residents in these facilities are likely to increase as they age, as a large number will reach 60 years or more in the next 15 years and, as other countries have found,[15] this will probably lead to competing financial demands for increased investment in existing residential facilities and those aimed at boosting community health services to maintain people with ID within their family structures. There are strong arguments for future planning to commence timeously with the aim of seeking more cost-effective models of service provision for this group.

Regarding improvements to current health service provision, greater attention should be paid to mental health, management of challenging behaviours, and medication issues for persons already in residential settings and the greater number currently living with families. If these issues can be dealt with at a primary level, the possibility increases of enabling adults with ID to continue to live within their families or communities; this in turn would reduce the need for provision of more residential facilities and enable greater participation of people with ID in community life. Many will nonetheless require carers to assist with their daily living needs. Supporting a person with ID is a lifelong commitment, and carers, whether family members or paid employees, warrant support to sustain their caring roles.

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