

# Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa

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Accepted for publication 29 June 2015

**Background** Internationally adults with intellectual disability are largely cared for by their families, especially in low- to middle-income countries (LAMIC). Compared to high-income countries, little is known about their experiences in LAMIC such as South Africa. **Methods** Focus group discussions were carried out with 37 family caregivers (FCGs) in the Cape Town metropole. These were transcribed and analysed thematically. Core categories were identified and validated through member checking.

**Results** Family caregivers showed strong commitment to care despite the heavy responsibility and burden of care

that women especially experience. They recognize the limited personal growth opportunities for people with intellectual disability that increases the caregiving burden. FCGs identify supports and resources in the community that assist them with their care responsibilities but often feel let down by services.

**Conclusions** Improved family supports appropriate to the resources in LAMIC are needed especially when existing carers are no longer able to provide care.

**Keywords:** adults with intellectual disability, care, family caregivers, South Africa

## Background

In common with most low- and middle-income countries, nearly all adult persons with intellectual disabilities in South Africa live in the care of family members (McKenzie *et al.* 2013). The extra stresses that family caregivers (FCGs) experience in more affluent countries has been well documented for children but less so for adult persons. In these countries, support services have developed to assist families in their caring role so that they and their disabled relative may have a better quality of life (Families Special Interest Research Group of IASSIDD, 2013).

However, the available knowledge drawn mostly from high-income countries about family caregiving and appropriate support services cannot be assumed to apply globally (Hatton 2004). Yet the need to support families in poorer countries is arguably all the greater for three main reasons. First, the higher prevalence of

intellectual disability in low-income countries allied with the increased life expectancy of children with developmental disabilities worldwide means that more children are surviving into adulthood during which many will continue to need lifelong care and support. Thus, there will be even more families in the future caring for adult persons with intellectual disabilities (Maulik *et al.* 2011).

Second, it is well recognized that families with disabled relatives are particularly disadvantaged and this is even more marked in low-income countries. They are generally poorer, experience greater ill-health, live in more impoverished settings and are more socially isolated (Inclusion International, 2006). The impact of the HIV/Aids epidemic has meant that traditional caring roles of parents have been altered (Groce 2004) with grandparents and other family members having to become caregivers.

Third, less affluent countries cannot afford the costs involved in the provision of paid carers in residential

and supported housing schemes that enable people to live away from their families if that is their choice or when family carers are no longer available (WHO, 2011). The only viable alternative for the short and medium term is family care in some form or other. The aspirations contained in the UN Convention of Rights of Persons with Disabilities (2006) can only be attained through the active participation of families and the upholding of their own human rights. For all these reasons, family care in middle and low-income countries is critical in ensuring that adult persons with an intellectual disability have a reasonable quality of life.

It is worth recalling that these three arguments apply globally. In past decades, families in the affluent countries of today would have experienced many of the deprivations that are now common in low-income countries. But progress came about through parental advocacy and as part of the wider community development of health and social services rather than investing in institutional care. The same processes can be mobilized to effect change in low-income countries in readiness for future economic growth and prosperity, the signs of which are emerging in some African countries (International Monetary Fund, 2013).

A key starting point is to make known the reality of the caring experience for families. Although international research studies have a contribution to make to doing this, locally garnered information from low-income countries is more potent. McNally & Mannan (2013), in their study on FCGs in Tanzania, note the objective difficulties that parents experience due to systemic poverty and the additional resources required to fulfil the caregiving role. Parents also experience difficulties that arise from the subjective emotional challenges when dealing with the stigma of disability. However, these parents also recognize positive aspects of family caregiving such as observing the progress, development and good health of their children. Aldersey (2012) who also conducted interviews with parents in Tanzania identified family strengths that include commitment to the family and advocacy for their disabled family members in the face of stigma.

Further local research studies should also help to validate the common experience of carers and will assist in identifying culturally appropriate support services for families as indigenous practices and community-based responses to these problems have not been explored (Njenga 2009). For example, Aldersey (2012) identifies the needs of parents to understand the cause of their child's difficulties and suggests that they should be

supported in doing so using both Western and traditional health practitioners.

The South African census of 2011 established a prevalence rate of disability of 7.5% (2 870 130 persons with disabilities) based on the Washington Group questions. These questions rely on the reporting of the degree of difficulty experienced within the functional domains of seeing, hearing, communication, walking, remembering or concentrating and self-care (Statistics South Africa, 2014). The Black population has the highest disability prevalence at 7.8% compared to 6.5% in the White and 6.2% in the coloured group (in the South African context, 'coloured' refers to people of mixed ethnic origin). However, it is hard to identify in this data the difficulties that correlate with intellectual disability. Local surveys in rural South Africa identified a prevalence rate of 3.6% among children of whom 0.6 per 100 had severe disabilities (Christianson *et al.* 2002).

It was against this background that the present study was conceived. South Africa provides a range of socio-economic conditions – some equivalent to high-income countries but with many more areas similar to low-income countries, particularly in the townships and rural villages (Statistics South, 2003). The extent of service provision is limited nationally and is often provided through non-governmental organizations (NGOs) rather than government structures (Adnams 2010). Within the South African context, the inequalities of provision originating in racial discrimination (Foster 1990) remain an abiding feature of all disability services. Under apartheid, Black people received the least services, followed by the coloured group and then by those classified as Indian. In all cases, provision for the White population was the major focus of state spending. While these racial divisions have no place in legislation in South Africa today, the structural inequalities persist and, despite the growth of a Black middle class, may even be increasing (Kings 2014). The findings and the methodology used in this study could have relevance to other African contexts as well as application internationally.

## Aims

The aim of this study was to explore the experiences and concerns of parents and other FCGs from various races and classes relating to their caring for an adult relative with intellectual disability in the city of Cape Town in the Western Cape Province (WC) of South Africa.

## Method

Ethical approval for the study was given by the Human Research Ethics Committee of the University of Cape Town (HREC reference number: 429/2011), which requires compliance with the Helsinki Declaration (World Medical Association, 2008).

A qualitative research methodology using focus group and individual interviews was used for data collection. A semi-structured interview was conducted using an interview schedule covering issues such as who is responsible for care, what are some of the challenges that families face and what support they would like in caring for their son or daughter. This schedule ensured that the same topics were covered in all interviews in a spontaneous manner and that participants felt free to contribute on their own experiences (Hesse-Biber 2007). The group facilitators were from similar language and cultural backgrounds as the participants thereby creating an atmosphere conducive to sharing experiences (Puchta & Potter 2004).

Family caregivers were recruited through residential facilities, employment programmes and community-based organizations. The services reflected the racial mix of the Cape Town metropole and the range of living circumstances of families. The organizations were informed about the research and asked to distribute letters of invitation to their parent members. The research assistants then followed up on those who responded and set up a time and date for the focus group interviews. FCGs of adults in residential facilities were included even though they were not presently responsible for day-to-day care, but the circumstances of relinquishing this care were thought to be of value in understanding the pressures that family carers experienced.

Five focus groups were conducted as well as two individual interviews in cases where the FCGs did not want to address the issues in a group context. In most cases, the parents were interviewed at the premises of the recruiting organization. The interviews were conducted in English, Afrikaans and Xhosa. For each of these language groups, a native speaker of the language conducted the interview.

## Participants

In total, 37 participants were interviewed in groups or individually, with five of these being male and 32 female. These caregivers were largely mothers (26) with a few fathers (5), sisters (3) and three other

relations (namely aunt, grandmother and legal guardian). In all, 14 were Black, 13 White and 10 coloured.

In two cases, the mother and father both participated in the interview as caregivers of the same individual with intellectual disability. Twenty-four of the adults with intellectual disability lived at home and 11 in residential facilities. Only one caregiver described an independent living situation for her daughter who shared a flat with a friend. The gender of the adults with intellectual disability about whom the caregivers spoke was predominantly female with 27 women and only nine men. The bias towards females with intellectual disability appears to be an artefact of our recruitment strategy as the participating residential facilities were for women only. The age range of relatives with intellectual disability was from 23 to 68 years.

## Data analysis

Interviews were recorded, transcribed and translated where necessary. The approach to data analysis was informed by grounded theory. Two researchers read through the transcripts identifying open codes or themes making use of the qualitative research software Dedoose (Lieber *et al.* 2011). Through the method of constant comparison of the themes, cases and categories for similarities and differences, they worked towards the development of core categories that would enable them to describe the data in an analytic way, moving away from the descriptive level to a conceptual framework that synthesized the caregiving experience with one core category emerging. The resulting categories pointed us to further interviews where participants were selected in order to develop the emerging framework by means of theoretical sampling (Pidgeon & Henwood 2004). Finally, we presented the core categories to a group of FCGs who had participated in the original focus groups for member checking who confirmed the identified categories. This indicated that a satisfactory degree of data saturation and authenticity had been achieved as the participants expressed the view that the core categories reflected their own experiences.

## Findings

Figure 1 shows the categories generated in this study and the proposed relationship among them.

In summary: the core category to which all the others related was *commitment to caregiving* with the two

elements of *responsibility for care* and *burdens of caring*. FCGs accepted and took on *responsibility for care* even when their relative lived away from home. Overwhelmingly, it was women who took on care responsibilities which highlights the important *gender issues* around the provision of care. The responsibility for care was mediated by the *community supports* available to the primary carers which enable them to pursue their own goals while not neglecting their caring responsibility. The *burdens of caring* were evident and exacerbated by families reporting a feeling of being *let down by services*. The care burden was greater when the *personal growth and development* of the person with intellectual disability is limited as they require higher levels of care, in terms of both time and intensity. The intense responsibility of care makes the FCG extremely anxious about the *future options* which for the most part were extremely unclear to our participants. These categories were apparent across all types of family carers and racial groupings, a noteworthy finding in itself.

**Commitment to caregiving**

At the centre of the experiences of these FCGs was their commitment to caregiving which was expressed in their recognition of the continuing responsibility that they have for care of their family member with intellectual disability despite the burdens placed on them.

**Responsibility for care**

Family caregivers accepted their responsibility to care without question and expressed the strong commitment to do so:

I take care of my child because it is my full responsibility God gave it to me. (FG4)

Family caregivers take this responsibility very seriously as they see themselves as the protectors of their family members in a hostile world:

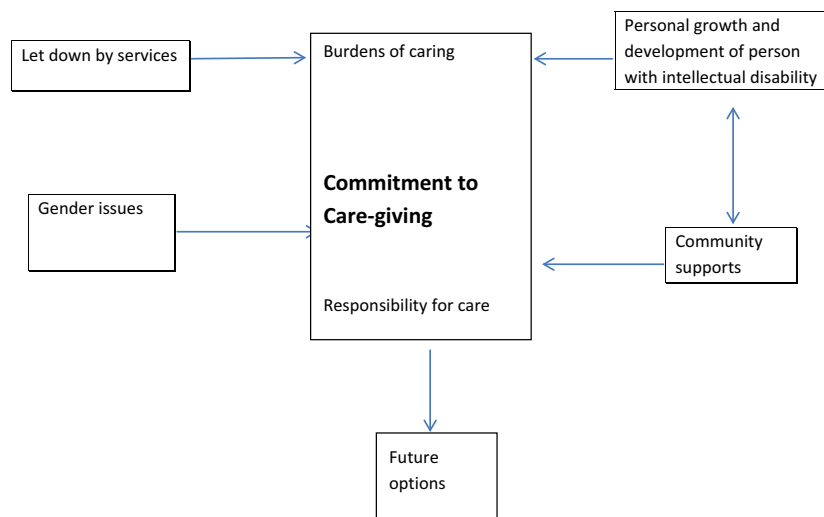
I must always be alert because there are so many strange things happening outside: maybe she can be raped that is why I am so careful and happy to look after her (FG5)

This degree of responsibility is reflected in intense and close care relationships:

I am a bit too sort of, joined to P. at the hip to really easily, you know, sort of think about it too dispassionately (FG1)

The responsibility is often borne with pride and a deep faith:

I left my home to look after my grandchild so that she cannot be abused, she cannot look after herself,



**Figure 1** The categories of care-giving as perceived by South African family carers.

she needs supervision full time. I am asking God to give me more days – I just think: if I should die who is going to look after her the way I want. (FG5)

Most saw no end to their caring responsibilities and feared the future.

We would be there for [our children] at any time they want us. It is the future that is important here whatever that can come up that can allay our fears for the future that we would appreciate so much. (FG3)

### *Burdens of caring*

Intertwined with carers' comments on their taking responsibility for care were descriptions of the burdens this placed on them and the toll that this took on their own health:

It is not easy to wash them, you have to lift her up, I suffered from back-ache. I think they need to have separate bathroom that is equipped with standing frame which will make easier for us to wash them. It is worse for us staying in the shacks because we do not even have decent toilets. (FG4)

Finance poses a great problem, both because of the additional needs of their child and because of the inability of FCGs to work because of their caregiving obligations:

Even for her that money is not enough (Disability Allowance), paying transport money, buying food. Looking after the entire household it is difficult because I cannot work and need to look after other children (FG5)

Mothers are also called upon to take care of their children's healthcare needs which can be very difficult:

L. had an outburst and I took her to trauma /.../ the doctor asked me: do you want to put her away...I said away? what are speaking about? I said this child just had an outburst; I know this child...you can give her tablets. (MC)

For parents relying on public transport, there are challenges, as they cannot go out easily especially if their child also has a physical disability.

Transport is the challenge and necessity. Our children got sick anytime, people do not want to help you at night (FG4)

There is a high degree of stigma associated with intellectual disability.

The community need to be educated about intellectual disability and stop calling our children *izidalwa* (deformed child). They are people like the rest of us, need to be treated with respect. (FG4)

Family members with intellectual disability often internalize the stigma and live with a sense of failure in themselves:

I can tell you when we get fancy people that visit the house, W. won't go near them. She would just go to her room because she thinks people are looking at her so she would rather go into the bedroom and eat there. (FG3)

To some parents, it was a great source of sadness that the presence of the person with intellectual disability in the home results in their siblings also isolating themselves:

My son would never ever bring friends home /.../I said to him 1 day is that because you are embarrassed about your sister...and he wouldn't answer me... (FG2)

Parents of adults with severe behavioural difficulties found themselves extremely isolated as it became difficult or embarrassing to take their child out:

July last year my mom passed away at age 87 and I couldn't go to her funeral. There are too much people and the church would be full. You can only imagine how (my daughter) will perform in that church and I would have disturbed the whole congregation. I was very heart broken: it is my mother but, what can I do but, still I was not going to disturb everybody else. (FG3)

Pervasive negative attitudes contribute to the social isolation of families and the fear of abuse exacerbates the burden of care due to the constant supervision required which leads caregivers to isolate their child as a form of protection for them.

Here bad things are happening in our community. One disabled child was raped and killed found after several days missing. When you hear those stories you become afraid for your child to go out. (FG4)

The emotional consequences of care and having to be available for care all the time can lead to depression and even to thoughts of suicide. Some parents have resorted to physical violence against their children out of frustration:

But, sometimes when she is difficult I tell her you can't be rude to me I am your mother...My mother always use to moan at me not to give M. a slap she said this child is a disabled child. Then I said to her: she is disabled but she knows what she is doing. (FG3)

Some carers also reported being assaulted by their relative. As the person gets bigger and older, this is more of a threat to ageing carers.

She won't try to hit me because I pushed her against the wall once: I said to her, I am the one who is looking after you, I am your mother you are not my mother. (FG3)

Families depend heavily on the involvement of siblings in the care of their children with intellectual disability, particularly in single-parent households. At times, this can be very demanding:

At 14 he was taking responsibility for a 18 year old who wanted her own way and who wanted to do things her way and who was verbally abusive towards him. He was developing nervous habits at an early age ... (FG2)

As the parents begin to age and have difficulty coping, they begin to expect more from the siblings:

I think of the future and look at my wife that is bedridden and can't get up; I am 78 and all my other children are married. Once they get married, they get their own babies. When I ask my son or my daughter to come here and say - dad needs you, mum needs you - they turn their back and just say mom dad I have got so much to do. (FG3)

Some more affluent carers had reluctantly relinquished care and sought out a residential home for their relative.

I did nursing for many years and I can see that he really needs nursing care but I would never take it upon myself not at my age, and that is why we got these facilities for them. (I2)

### Personal growth and development

Carers recognized that the lack of personal growth and development opportunities for their family member contributed to their relative's frustration which in turn made the caring role even more difficult. After finishing school, there are extremely limited pathways for the young adult to find meaningful occupation or employment.

She is over 18 and when she was told she cannot go to school, I said she can stay at home with me again, she can sleep anytime she wants. (FG4)

This means often they will be sitting at home with little to do:

When I go to sleep, she shows me in what station she wants the TV. She watches a lot of TV till late at night; long past we have gone to sleep. She just shows me when she wants me to change the station for different programmes (FG3)

However, some carers expect their relatives to do household chores:

He has to make his bed, puts his clothes away. He is responsible usually for putting the clean dishes away, laying the table and putting the clean washing away, putting the lights on sometimes in the evenings in winter. Making his own sandwiches (FG1).

Many parents expressed concerns that their relative is unable to occupy him or herself and in the absence of friends become isolated or bored.

P. can end up with time on his hands, he needs guidance to some extent to occupy himself meaningfully at home, whereas if he was part of a bigger community that would be taken care of more readily. (FG1)

Yes they are very frustrated at home and my wife says that when he gets frustrated he will pick up the first thing he sees and throw it at the window (FG3)

Overall, there was little drive or awareness of their child taking on adult roles such as having a job, except in FG1, the more affluent group. When parents speak of their relatives attending workshops, they refer to them as 'schools' and do not appear to see them in relation to earning a living or preparation for work:

I have noticed a difference here at her school [sheltered workshop]; her memory slowly coming back; she remembers to give me letters or any correspondence from school and before she goes to school the next day, make sure the feedback is in her schoolbag. (FG5)

There is a great deal of concern and anxiety about the development of sexual relationships, ranging from sex education -

It still always bothers me with A. because we've never sat down and talked to him about it. Do they ever think still that they might go on and live independent lives, get married, do anything like that./../does anybody discuss it with them? (FG1)

- to a passionate concern about sexual abuse:

I said to her if any man touches you at that school; any person whoever it is even the van driver or whatever and he touches you: come and tell me and I will kill him – finish. (FG3)

#### Let down by services

Family caregivers had many stories to tell about how they have been let down by services, whether these be from the State, from NGOs or from paid helpers. As regards the State, they find it difficult to access appropriate health services, partly due to the costs of transport and partly due to a lack of understanding of healthcare providers:

What I must say and I am repeating it; in 2005 at X Hospital they gave her too much drugs and this is the cause. There is a teacher that when she came here said she is different, she is completely damaged by the drugs they gave her. (FG3)

At times, social workers seem to be at a loss as to how to assist these parents:

I need help I need support but, I don't really know, I have been to [social work NPO] I don't know how many times. (FG3)

Paid caregivers cannot be trusted to look after their children:

When I was working together with my mother, we had a care-giver who was looking after my child, she was coming late make it difficult for us to get to work on time. We locked the house hoping she is coming soon but neighbours told us she comes at 2 pm since we left her in the morning, I decided to stop her and took my child to a day centre. (FG4).

Parents in one area expressed their frustration that day care centres and workshops were not available in their community and would be most welcome to get their children out. These women felt let down by local government leaders who did not seem to offer them support when they took up the challenge of providing services themselves. In these areas, the carers were mainly single women who are living in poverty:

If our communities want it to be better place, more work needs to be done before that can happen. Our leaders are corrupt, poor people suffer. There is no improvement at all. (FG5)

The need for respite care was also not being met and in fact provision appeared to have declined over the past few years:

She use to go to X hospital for relief but that was also taken away now I don't know why; they didn't say anything. She used to go three times the year for 6 weeks and then I could have a break. It was most welcome for me. (MC)

Some parents have tried to find more affordable residential care for their children with disastrous results:

I struggled a lot at the beginning when I took her to these places (residential) when I find my child lying with bed sores. That is when I decided to take care of my own child. I was young and frustrated but I told myself: my child deserve better and I will give her love until the end. (FG4)

Other parents also expressed their disappointment in the residential care provided but felt they were not in a position to do anything about this unhappiness:

He also does not have a lockable cupboard for his private things. There is always some theft. Sometimes

when we come to visit we see that he wore the clothes that are not his own and do not fit him. (I1).

### Community supports

Despite the many difficulties and burdens that parents faced, there were supports and resources that they made use of to help them with their caring responsibilities. One of their greatest supports is their religious faith that gives them spiritual strength to carry on with a task that is often seen as a lonely burden:

So I go down on my knees still every night and I believe, if you are sincere, God would provide. Before I used to be a different person but, today without Him I am lost. Every step I take is in His name. (FG3)

On the whole, families were the main form of support to caregivers, notably siblings as indicated above.

Other family members were also helpful:

My family is supportive, all of them, they take turns to take him out and buy gifts, they all love him. (FG5)

One mother appreciated the support of community-based rehabilitation workers and was able to manage with their help:

She is not physically disabled at least I manage to cope with her with the help of health workers from (community based organisation). (FG4)

Parents also appreciated the work done by some service providers in supporting their children. The day care centres and sheltered workshops were highly valued as was the level of care in the one residential facility.

These workshops are very important when the child is over age for their school they need a place where they will keep them busy, learn handwork something to keep them busy, remember they are growing old now, they also have feelings for the opposite sex. (FG4)

### Gender issues

The issue of care for adults with intellectual disability is a highly gendered one that intersects with race and class. For Black families, caregiving was invariably women's

work. Amongst the more affluent White families and coloured families, care was shared between the two parents with less dependence on siblings who played more of a backup role than engaging in hands on caring. There was also evidence of discomfort on the part of male family members in dealing with their children:

L.'s father doesn't visit as often and I have to tell him to come and visit her and bring her something. I always had the sense that he was embarrassed to have a disabled child. (FG2)

This can lead to the total abandonment of the family:

I as her mother care for my child. Her father was not there for me, I had to stop working and take care of my child (FG4)

Fathers expressed concern for the financial and physical safety of their children quite strongly, whereas mothers focused to a greater extent on physical care with a high priority attached to physical cleanliness. One of the challenges expressed by several mothers was the difficulty dealing with their daughter's menstruation, whereas others had solved this problem through allowing their child to undergo a hysterectomy:

she could not keep herself clean properly and they advised us to have it [hysterectomy] done sooner than later – because it was injections otherwise: the pill which is not suitable for them. (FG2)

### Future options

Given the degree of responsibility that carers had assumed for their relative, a major concern was who would assume this responsibility once they were unable to do so. Their focus was to maintain continuity in the care they had provided.

They have grown up in certain atmosphere and you'd want a similar background. So you'd want a home. I would want something more like what he's used to at home. (FG1)

They expressed concern that their child should be cared for and kept clean and well fed:

To be under the care of a person who will look after her, person you trust that will do your usual



things, make sure she is clean, wearing clean clothes, eating properly going to school, things that you usually with your child. (FG5)

They also felt strongly about the need for protection from sexual matters:

When she started to menstruate I ask God for protection I was thinking of pregnancy, I said God do not let her have a child because in her situation she is a child herself if she can have a child how will she take care of that child because she is being taken care of herself. (FG5)

Some parents wanted their children to live in a pleasant environment and to be happy living in a childlike world:

A place that will make them feel like normal people, to be loved and accepted with everything they need that will make them explore their talents. They are like children- if they do something for themselves they become happy. (FG5)

There was very little mention of companionship and relationships that their child might have in these living arrangements, but some parents voiced their concern that they would like to know the people sharing a house and they were the right type for their son or daughter:

If A. moved into a house I'd like to ...be able to identify with all of them and with their parents so it would be like a home, it would be like being with relatives. (FG1)

The historical lack of provision for Black people in South Africa is also reflected in the statement by one mother that she would like her child to be able to live like a White child;

I wish African children can live like white children. I have seen intellectually disabled white children's places, they are so beautiful, well equipped according to their needs, they have everything they need my wish is for our mentally disabled children to have places like that. (FG4)

## Discussion and Conclusions

The findings from this study cannot be claimed to be representative of FCGs across South Africa let alone

continental Africa as the sample was confined to one geographical area. However, the study does give voice to the experiences of carers that to date have been rarely heard, Africans from various races caring for an adult person with intellectual disabilities. This voice is one of commitment of parents to caregiving and in particular by mothers. However, the whole family is involved to a greater or lesser extent although as siblings leave home, the ongoing responsibility remains with ageing parents. This commitment is often evident from birth and in most cases lasts a life time. More remarkable still is that the caregiving is maintained despite the burdens and limitations it places on the family which are especially marked when their relative has higher dependency needs. It is a symbiotic relationship. The burden increases the sense of responsibility: for who else could provide comparable care?

In the absence of tangible supports, parents often have to fall back on their personal resources such as their religious faith and beliefs and focus also on the positives they experience from their caregiving. This can be especially testing in societies in which the stigma of disability is very real; yet often it has been through the advocacy of family members that discriminatory practices have been challenged (see e.g. Aldersey (2012)). Once again, adversity seems to heighten the responsibility of caregivers to their role.

In many respects, the themes identified in this study echo those reported previously for families in other countries, especially the combination of the burdens of caring alongside the gratifications parents also obtain (e.g. Grant *et al.* 1998; Families Special Interest Research Group of IASSIDD 2013). As Grant *et al.* (2007) argued, our understanding of family caregiving has to move beyond a focus on the stress and strains parents experience towards identifying the psychosocial drivers for building resilience within families. In less affluent countries, the scarcity of material, social and cultural supports for families would seem to lessen the prospects for mothers to sustain their caregiving role and yet the data from this study suggest otherwise. Many do cope despite the adversities they encounter. In 'resource-poor' settings, the internal resources which parents bring to the caregiving role then take on extra significance and yet little research has been undertaken internationally into this dimension of caregiving. Arguably the insights to be gained by studying families in low-income countries would be particularly valuable. Looked at from a wider societal perspective, families provide an invaluable material resource in the care of adult persons with intellectual disabilities. If governments are to take

seriously their commitments under the UN Convention on Rights of Persons with Disabilities, then tangible support for families must feature strongly in their policies and practices. Yet a strong message that came from the families in this study was of being 'let down by services'. Perhaps this is not too surprising given the relative dearth of support services in middle- and low-income countries. Nonetheless, this feeling of being let down is also reported by parents in 'service-rich' settings of high-income countries (Grant & Ramcharan 2001; Bigby & Fyffe 2012) which suggests a deeper interpretation is needed. One possibility is that carers are expressing a lack of appreciation by services of their caregiving role and a failing to understand their situation and needs. The strategy proposed in high-income countries of moving to more 'family-centred' approaches is worthy of emulation in less developed countries (Davis & Gavidia-Payne 2009). Indeed, the families in this study who had experience of home-based community support spoke of the value this had been to them personally as well as to their relative. This links back to building the caregivers' internal resources as a primary means of building their resilience.

The lack of opportunities for personal growth and development of their relatives was a particular concern to families. This added to their burden of care and restricted their consideration for future care arrangements. The lack of education and training in many low- to middle-income countries reduces chances of obtaining paid employment for people with intellectual disability (McKenzie *et al.* 2013). A 'care ethos' tends to dominate, with family carers getting little opportunity for a break from their caring role and little incentive to contemplate a more ordinary life for their relatives. A priority therefore is to develop community-based education, training and leisure options that will further the competence of persons with intellectual disabilities to become more self-reliant at home and provide opportunities for them to engage in activities outside of the home (Cramm *et al.* 2014). Failure to do so will result in many persons needing higher levels of care and at greater cost than might otherwise be the case.

In common with their counterparts in other parts of the world, African parents were also concerned about the future. Arguably their concerns were heightened due to the lack of services available to them. Future planning is promoted internationally as a means of assuaging some of these concerns but also a stimulant for service development. In many low-income countries, local action is required to counter government disinterest (Geiger 2012). Often the leadership has come

from parent associations linking with NGOs to provide supported living and group homes in their locality although the ongoing funding of such initiatives is often problematic. The issue of out-of-home care for persons with intellectual disability will become of increasing importance as more people with intellectual disability outlive their parents. To date, it has received relatively little attention from policymakers and even advocates.

Given the challenges that face FCGs in the study context, the lack of collective conversation and action amongst the caregivers needs to be challenged. Further research needs to explore how families can advocate locally and nationally for their own support needs and those of their family members requiring care. The UN Convention on Rights of Persons with Disabilities provides a focus for them but without a concerted campaign supported by families, it is unlikely that desirable changes will occur (McConkey *in press*).

### Acknowledgments

The authors acknowledge the valuable contribution made to this paper by Professor Colleen Adnams, Vera Grover Chair and Professor of Intellectual Disability, Department of Psychiatry and Mental Health, Faculty of Health Sciences, University of Cape Town. We would also like to thank our research assistants Elizabeth Seabe and Dominique Brand for the contribution of their considerable skills to this project.

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