

# CHAPTER 4

## UNPAID CARERS OF PERSONS WITH DISABILITIES IN AFRICA AND LATIN AMERICA: GENDER, HUMAN RIGHTS AND INVISIBILITY

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### Summary

*Care is a complex issue that may be analysed using different perspectives and theories. It is also a biological imperative for human beings. For many people with disabilities, assistance and support are prerequisites to perform daily tasks and participate in society. In most cases, family is the primary provider of care and support and, within families; care is a role that falls disproportionately on women.*

*The issue of unpaid carers (sometimes referred to as 'caregivers') may be analysed in terms of the gender equality impact that this role has as well as its social equality and human rights implications. Due to the fact that caring relationships involve carers as well as those they care for, public policies face the challenge of addressing the needs and claims of two groups which are different but related.*

*In developed countries such as the United States, Spain and Australia, governments have developed policies to address this issue. In contrast, Africa and Latin America show that it is still an invisible concern. Family caregivers provide care in conditions of fragility and lack of resources that allow situations where the rights of persons with disabilities are violated and rights of their family are ignored.*

### 1 Introduction

'Care' is a multifaceted<sup>1</sup> and complex concept as it can be used in various contexts, and its meaning and significance may differ through different

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1 J Swainet *Controversial issues in a disabling society* (2003) 141.

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societies, cultures, families and individuals.<sup>2</sup> Shakespeare asserts that ‘giving and receiving care is a biological imperative for human beings’<sup>3</sup> because at some point in the life cycle, almost all people may be involved in it. Caring can be expressed in different ways such as giving practical assistance, advice, emotional and social support. This paper is focused on informal carers (caregivers), people who provide unpaid assistance to members of their family, friends or neighbours who are elderly and/or have a physical, sensory or intellectual disability.

Caring is a role that falls disproportionately on women, it ‘is seen to be culturally appropriate to women’. Although caring is not an exclusively female activity – across the world, women and girls commit substantially more time than men to provide informal care.<sup>4</sup> It is this factor combined with a general lack of other support services provided by states that ‘encourages women to take on the role of carer’.<sup>5</sup> As result, the issue of informal care involves notions about gender inequalities. At the same time, it is inextricably intertwined with other structures of inequality, especially race and social class.<sup>6</sup>

In the domain of human rights, the UN Special Rapporteur on extreme poverty and human rights has highlighted the relational nature of care – in which ‘the rights of caregivers are symbiotically intertwined with the rights of care receivers’. It is a dynamic relationship where the well-being of the caregiver ‘has an impact on the quality of the care they are able to provide’.<sup>7</sup> Therefore, if informal care is not adequately recognised, supported or valued by the state, the rights of those who rely on care provision for their health, life and well-being may also be violated. In such a ‘caring relationship’ the rights of both caregiver and the carer receiver are inextricably linked. This paper focuses on these complexities and at a macro level, it explores the historical difficulties in the relationship between the emerging disability rights movement and the carers’ movement.

- 2 JD Joubert ‘A profile of informal carers in South Africa’ unpublished MA dissertation, University of Pretoria, 2005 1 <http://hdl.handle.net/2263/30044> (accessed 10 March 2015).
- 3 T Shakespeare *Disability rights and wrongs* (2006) 135.
- 4 See D Budlender *Time use studies and unpaid care work* (2010); United Nations *The world's women 2010: Trends and statistics* (2010); World Health Organization *World report on disability* (2011); V Esquivel *The care economy in Latin America: Putting care at the centre of the agenda* (2011).
- 5 E Begley & S Cahill ‘Why women?’ (2003) 92 *An Irish Quarterly Review* 163.
- 6 S Razavi *The political and social economy of care in a development context: Conceptual issues, research questions and policy options* (2007) iii.
- 7 M Sepúlveda Carmona ‘Report of the Special Rapporteur on extreme poverty and human rights’ A/68/293, 9 August 2013.

## 1.1 The human rights context

Informal care has been positioned as a human rights issue because its heavy and unequally borne responsibilities create a barrier to gender equality and to women's equal enjoyment of human rights. It also has significant impact on the health and well-being of the informal carers. As result, the rights and well-being of people they care for may be threatened. It would appear to follow that a failure by a state to adequately provide, fund, support and regulate care would contradict their human rights obligations, by creating and exacerbating inequalities and threatening rights enjoyment for those involved in the caring relationship.

The UN Special Rapporteur on extreme poverty has been emphatic on her arguments: States' actions or inactions define who has access to quality care and who assumes the costs of its provision. Thus, 'when the State fails to adequately regulate, fund or provide care, the burden shifts to families who have to make their own arrangements', it may lead in an arrangement that threatens the rights of enjoyment for both informal carers and people with disabilities. Therefore '[s]tates must adopt all necessary policy measures in order to achieve the recognition, reduction and redistribution' of informal care. Public policies should position care as a social and collective responsibility rather than a private and familiar issue, 'and treat unpaid caregivers and those they care for as rights holders. A transformative approach is clearly required under human rights law'. As the causes and consequences of informal care inequalities are multi-layered, multiple and complementary,<sup>8</sup> it is central to develop complex policy interventions that asserts the rights and need of both parts involved without benefiting one above the other.

Research on informal care in developed nations is well established and extensive. States have conducted surveys in order to gather reliable information about who carers are, where they live, how they live and how many there are. Using this information, states have applied comprehensive public policies to address the rights of informal carers of people with disabilities. Spain, Australia, UK, New Zealand and United States are examples of this.<sup>9</sup>

However, the issue of informal care has received very little attention in Latin America and Africa where statistical information is scarce. Malherbe states that in Africa families have the duty to care for family members with disabilities, but 'this preference does not translate into sufficient statutory

<sup>8</sup> Sepúlveda Carmona (n 7 above) 69-71.

<sup>9</sup> See S Yeandle et al 'Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland' (2012) 22 *Journal of European Social Policy* 432; H Arksey & M Morée 'Supporting working carers: Do policies in England and the Netherlands reflect "doulia rights"?' (2008) *Health and Social Care in the Community* 16.

assistance, or into significant practical assistance to caregivers'.<sup>10</sup> The same situation occurs in Latin America where many countries have laws that oblige family members to provide assistance or help (also the economic obligation) for their relatives but make little or no provision for compensatory support for such carers.<sup>11</sup> As Clements notes, in much the same way that the English Poor Law obligation to care for family members was exported to its colonies, the Spanish Civil Code obligation (the duty on family members to provide '*alimentos*') was exported to much of South America.<sup>12</sup>

The social organisation of care in Latin America varies depending on different family dynamics, labour markets, economic structures and traditions. Nonetheless, current data show a number of common features that characterise the social organisation of care in the region, including the fact that care continues to be a function mainly of families, and women within families. It is therefore a matter that is considered to be mainly private.<sup>13</sup>

The dearth of carer specific information; carers' rights legislation and policies; and a carer specific research and literature in Africa and Latin America have the effect of making caregiving an invisible issue: one where carers are not seen as rights holders. Therefore, in these regions, informal carers face multiple obstacles: unemployment, weak health systems, inadequate social protection services and policies, and fragile economies. As result, informal carers and the people they care for frequently live in a situation of extreme vulnerability.

The first part of this paper addresses the concept of care and tackles the development of the carers' rights movement and its theorists. Moreover, this section analyses the gendered nature of informal caregiving and deals with the conflicting relationship between the carers' movement and the disability rights movement.

The second part of this paper goes deeper into the issue of informal caregivers of people with disabilities and the human rights approach. This section analyses examples of public policies that other states have implemented in order to protect the rights of both parts involved in the caring relationship.

10 K Malherbe 'The social security rights of caregivers of persons with disabilities' in I Grobbelaar-du Plessis & T van Reenen (eds) *Aspects of disability law in Africa* (2011) 183.

11 L Clements 'Does your carer take sugar? Carers and human rights: The parallel struggles of disabled people and carers for equal treatment' (2013) 19 *Washington and Lee Journal of Civil Rights and Social Justice* 397.

12 As above.

13 K Batthyány Dighiero *Policies and care provision in Latin America: A view of regional experiences* (2015) 16.

The last two sections focus on the situation of informal caregivers of people with disabilities in Africa and Latin America. Due to the fact that these regions are vast, and bibliography about this subject is scarce, this paper compares the policies implemented in selected countries.

## **2 Care: Complexity, gender and debate**

There are very many dimensions to the concept of 'care': public and private; practical and emotional; commodified and uncommodified – and so on. This paper considers the position of those people who provide unpaid care for family or friends: in academic literature such individuals are variously referred to as 'informal carers', 'unpaid care workers', 'caregivers' and 'family carers'.

During the 1980s the rights of caregivers of people with disabilities attracted the attention of researchers and academics in Europe and North America. Feminist scholars in particular focused their analysis on making visible the nature and extent of this work carried out by women in the private domains of the family and home and the cultural and jurisprudential assumptions that this labour was somehow 'natural'.<sup>14</sup> As result, the issue of informal care was identified as a women's issue because caring is a role that falls disproportionately on women. It has an important impact in terms of their equality of opportunities with men. Many time-use studies<sup>15</sup> have demonstrated that women spend more hours than men in caring for members of the family. Discriminatory gender stereotypes, culture practices and the lack of public policies contribute to the perpetuation of this structural inequality. Thus, the carers' rights movement that emerged in the eighties, demands that governments take direct action to challenge this discrimination by developing measures that recognise, reduce and redistribute informal care. Caring policies include health protection and services, provide information, and support carers to balance their work, life and caring roles.

The 'World Report on Disability' states that many persons with disabilities need assistance and support to achieve a good quality of life and to be able to participate in society; most assistance and support comes from family members. State supply of formal services is generally underdeveloped, not-for-profit organisations have limited coverage, and private markets rarely offer enough affordable support to meet the needs of people with disabilities.<sup>16</sup> As a result, members of the families (generally women) have to assume the role of informal carers. This situation has led

14 M Fine & C Glendinning 'Dependence, independence or inter-dependence? Revisiting the concepts of care and dependency' (2005) 25 *Ageing and Society* 603.

15 See R Antonopoulos *The unpaid care work – Paid work connection* (2009); United Nations(n 4 above).

16 WHO *World report on disability* (2011) 137 [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf) (accessed 19 March 2015).

to a debate between the carers' movement and the disability rights movement.

The aim of this paper is not to develop an explanation of this debate but to clarify aspects of how the differences between the two movements arose and the role governments have played in creating these tensions. First, any state policy designed to address the issue of informal care of people with disabilities should address the needs and preferences of both parts in the caring relationship. This paper argues that in order to protect the rights of informal carers and the people they care for, states have an obligation to develop comprehensive and inclusive carers' strategies/legislation. As Rogero García explains, public policies should establish rights and duties around the care and also promote freedom of the people involved (carers and people with disabilities). A proper distribution of care responsibilities requires, firstly that a 'voice' is given to those who receive care and that their rights are respected, and secondly that the rights of those who provide the care (and the context in which that care is provided) are fully addressed.<sup>17</sup>

Feminist researchers have led the debate and discussion about care and carers' rights. Arguably, however, they have failed to include the experience of those 'cared for' and as a consequence limited the scope of analysis and as a consequence the potential for compensatory strategies. This paper seeks to argue that supporting informal carers does not necessarily result in less rights or protection for people with disabilities: that the relative impacts do not amount to a zero sum game. This claim is most obviously demonstrated by the fact that the well-being of informal carers has a major impact on those who receive care. As Twigg and Atkin have asserted, caring takes place in a relationship in which both parts are important. Caring cannot be examined separately from the needs and wishes of those they care for. At the same time, it is not possible to focus only on the person with disabilities, ignoring the existence of the informal carer and excluding them from concern.<sup>18</sup> Both, carers and service users, struggle with issues such as dependency versus independence, freedom versus obligation, and symbiosis versus oppositional interests. Consequently, the only way to deal with these struggles is by addressing the needs of both equality and avoiding the prevalence of one above the other.<sup>19</sup>

On another hand, Shakespeare states that debate on care and support should recognise that people are different so they have different support needs, aspirations, and values. Consequently, they need different forms of

17 J Rogero García *Los tiempos del cuidado: El impacto de la dependencia de los mayores en la vida cotidiana de sus cuidadores* [The time of caring: The impact of adults' dependency on carers' daily life] (2010) 330-331.

18 J Twigg & K Atkin *Carers perceived: Policy and practice in informal care* (1994) 6.

19 Fine & Glendinning (n 14 above) 617.

care in order to support them in ways that enable them to flourish and achieve their projects; whatever form of care and support is adopted, it needs to be based on respect for both parties – those who deliver care and support and those who receive it. Because the majority of humanity receives and gives care at different points of life and in different relationships, it is wrong to think in terms of opposed interests and separate groups.<sup>20</sup>

The rights of carers and the rights of persons with disabilities they care for are inextricably linked. For example, for people with psychosocial or intellectual disability, there may be circumstances where they need support from their carers to make decisions and exercise their rights. Article 12 of the Convention on the Rights of Persons with Disabilities provides that states parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. In terms of supported decision-making, family and other relatives (carers) may be central.<sup>21</sup> A policy that only assesses the needs of one part of this relationship has the potential to leave the other in an inferior position – which in turn may negatively impact on the other party. A failure to fully address the needs of carers risks therefore undermining relationships, creating dependency and denying autonomy for both, carers and people with disabilities.<sup>22</sup>

This analysis does not however deny the complexities and tensions that arise between those involved in this relationship. According to Shakespeare,

some voices in disability studies have failed to embrace the challenge of care, regarding it as an aspect of social oppression that can be eliminated, and replaced by the concept of independent living which can liberate *all* disabled people.<sup>23</sup>

This author agrees that care has often been the site of oppression and disempowerment since many caregivers (including families) do not recognise the autonomy, self-determination and even dignity of the people with disabilities they care for. As a result, states should develop systems of care and support that maximise independence and choice, and minimise abuse and paternalism. However, it is central to recognise that care and support relationships are complex, just as the people who receive care are diverse. Many people with disabilities have needs that will inevitably generate forms of ongoing dependency and have a strong preference for

20 Shakespeare (n 3 above) 151.

21 Usually people involved in supported decision-making systems want their families to participate in it. See 'Supporting decision making: A guide to supporting people with a disability to make their own decisions' [http://www.dhs.vic.gov.au/\\_\\_data/assets/pdf\\_file/0011/690680/dsd\\_cis\\_supporting\\_decision\\_making\\_0212.pdf](http://www.dhs.vic.gov.au/__data/assets/pdf_file/0011/690680/dsd_cis_supporting_decision_making_0212.pdf) (accessed 15 September 2015).

22 J Morris *Independent lives: Community care and disabled people* (1993) 156.

23 Shakespeare (n 3 above) 135.

informal care. Across the range of options, the important values should be accessibility, affordability, variety, choice, quality, flexibility and control; and developing public policies with this aim is central. In other words, it is unrealistic to claim that informal caregivers respect the autonomy, self-determination and dignity of people with disabilities, if they provide care without any training and without any form of compensatory support.

Public policies should not, as a general rule, subordinate the needs and wishes of one category of persons to those of another. In relation to dependency work, achieving this balance may not be easy but that should be the aim. It is central to develop a shared agenda and to adopt an approach that takes into account the relationship and common interests of both parties.<sup>24</sup> A good informal carer assessment is not about denying self-advocacy to people with disabilities because it should go along with an approach that enables those who receive care to speak up for themselves and be listened to. At the same time, the informal carer assessment may enable the carer to consider her or himself as a person with needs of her/his own.<sup>25</sup>

In 2001 Fiona Williams summarised a number of the above propositions when she noted that 'writers on the ethics of care, on independent living and disability, point to the need to link their strategies to a participatory democracy'<sup>26</sup> of giving people voice and choice. Those involved in care practices may begin to voice their claims and dialogues between unpaid carers and people with disabilities are central. These practices recognise 'different perspectives and identities, and aims towards a common vocabulary of values' because 'from each positioning the world is seen differently'. A comprehensive policy involves dialogue in which 'differences are seen as important, but not in hierarchical terms; they should encompass rather than replace equality; there is a recognition of the differences in identity and values'.<sup>27</sup>

### 3 Informal carers, rights and public policies

The main aim of human rights is transforming power dynamics between individuals in society, in order to challenge oppression, subvert the subordination and marginalization of certain groups and individuals, and promote individual agency, autonomy and respect of the inherent dignity of every human being.

24 V Williams & C Robinson 'More than one wavelength: Identifying, understanding and resolving conflicts of interest between people with intellectual disabilities and their family carers' (2001) 14 *Journal of Applied Research in Intellectual Disabilities* 31.

25 Williams & Robinson (n 24 above) 45.

26 F Williams 'In and beyond New Labour: Towards a new political ethics of care' (2001) 21 *Critical Social Policy* 483.

27 As above.



The unequal distribution of informal care is a human rights concern because it reflects and determines power relations between women and men; between families and relatives of people with disabilities and other families; and between those who can pay care services and those who cannot. States have a duty to act because these inequalities are obstacles to full human rights enjoyment. It follows that when any state fails in its duty and its public policies are inadequate 'either the cost of care is borne by the caregiver alone or the recipient of care suffers'.<sup>28</sup> Addressing the issue of informal carers is central because 'support systems and interventions can meet their needs, and local and national organisations can provide them with vital support in order to continue to provide care'<sup>29</sup> for their children, husbands, fathers and mothers.

The Convention on the Rights of People with Disabilities sees support and assistance as a means to preserving dignity and enabling individual autonomy and social inclusion. Equal rights and participation are thus to be achieved, in part, through the provision of support services for people with disabilities but also their families.<sup>30</sup> The World Report on Disability addresses the adverse consequences for informal caregivers when they performed this task without any support. Stress, disruptions to sleep and the emotional impact of care affect the caregiver's personal health. Moreover, informal care may result in loss of economic opportunities, as caregivers either reduce their paid work or refrain from seeking it.

To address these issues, policy responses should be comprehensive. Policies to address these deficiencies should not be seen as competing with the demands of people with disabilities – either in the context of independent living or of 'participation'. The needs and rights of the informal caregiver may be different from the needs and rights of the persons with disabilities so a balance must be found, so that each person has independence, dignity, and quality of life.<sup>31</sup> 'Across the range of options, the important values should be accessibility, affordability, variety, choice, quality, flexibility and control'.<sup>32</sup>

On another hand, the lack of policies to address the issue of informal care may lead to situations of discrimination. The landmark case *Coleman v Attridge Law*<sup>33</sup> confirmed, for the first time, the existence of (a European) concept of transferred or 'associative' discrimination. It is important to highlight that this concept was applied in a case that involves an informal carer. Sharon Coleman worked as a legal secretary, and was the mother of child with disability. She alleged that, when she returned from maternity

28 A McNally & H Mannan 'Perception of caring for children with disabilities: Experiences from Moshi, Tanzania' (2013) 2 *African Journal of Disability* 1.

29 As above.

30 WHO (n 16 above) 138.

31 As above 142.

32 Shakespeare (n 3 above) 146.

33 *Coleman v Attridge Law* (2008) 722 IRLR para 26.

leave, her former employer refused to allow her to return to her existing job; she was treated less favourably than other employees in comparable positions because she was the primary carer of a child with a disability. Moreover she was not allowed the same flexibility regarding her working hours as parents of non-disabled children; she was described as 'lazy' when she requested time off to care for her child, whereas parents of non-disabled children were allowed time off. In addition, she claimed that abusive and insulting comments were made about both her and her child. No such comments were made when other employees had to ask for time off or a degree of flexibility in order to look after non-disabled children. Having occasionally arrived late at the office because of problems related to her son's condition, she was told that she would be dismissed if she came to work late again. No such threat was made in the case of other employees with non-disabled children who were late for similar reasons.

In its judgment, the European Court of Justice held that she suffered discrimination by association: that the prohibition of direct discrimination is not limited only to people with disabilities.

Where an employer treats an employee who is not himself disabled less favourably than another employee is, has been or would be treated in a comparable situation, and it is established that the less favourable treatment of that employee is based on the disability of his child, whose care is provided primarily by that employee, such treatment is contrary to the prohibition of direct discrimination.<sup>34</sup>

This case provides an example about one aspect of informal care: they may face discrimination in their workplaces because of their caring role.

In political terms, Fiona Williams suggests an alternative to address the issue of informal care. She argues that an ethic of care needs to be developed: one that 'must drive our democratic practices deeper'. It has to involve dialogues between informal carers and people with disabilities. She suggests that the practices of transversal politics may be helpful because 'it recognises different perspectives and identities, and aims towards a common vocabulary of values.'<sup>35</sup> In public policies, the practice involves dialogue between informal carers and people with disabilities, in which differences are recognised and seen as important but not in hierarchical terms.<sup>36</sup>

Kittay is seen as an early and highly influential voice in identifying the need of informal carers for the support of others to ensure that their own needs are met (as well as those of the person they care for). They, who are predominantly women, can experience inequalities, disadvantage, and

34 *Coleman* (n 33 above) para 56.

35 F Williams 'In and beyond New Labour: Towards a new political ethics of care' (2001) 21 *Critical Social Policy* 483.

36 N Yuval-Davis 'What is transversal politics?'(1999) 12 *Soundings* 94-95.

they run the risk of poverty. Thus, Kittay argues that informal carers' efforts should be reciprocated by society.<sup>37</sup> In addition, applying a rights discourse, West addresses their disadvantaged position by proposing a more substantial demand. She states that informal carers should have the right to care and to be supported in this activity. This support may improve informal carers' well-being and provide some security while caregiving.<sup>38</sup> Furthermore, it may help to reduce women's disproportionate discrimination in terms of economic activity and gendered role differentiation.<sup>39</sup>

Given the challenges that informal care provision raises in terms of human rights (for informal carers and people with disabilities), some countries have made significant legal and regulatory changes in relation to care provision.

As a result, there are now laws and even constitutional norms that recognize care and the need to find a more equitable way of distributing responsibilities, both within the family and between public institutions.<sup>40</sup>

These provisions assume that caring for people with disabilities is an important contribution to their societies, help to reduce the dependence on long-term paid care systems and enable those living with health issues or disability to participate more fully in their communities.<sup>41</sup> In addition, by valuing and supporting informal carers, these provisions contribute in the development of strong healthy families that are able to help their members (those who receive care) to reach their full potential as participating members of society. This includes considering the impact of their role on carers' lives and the lives of those they support if carers' well-being is compromised. Caring policies include health protection and services, provide information, and support carers to balance their work, life and caring roles.

Countries that have enacted laws and public strategies to protect carers, have accepted caring as a shared social responsibility. These are focused on improving health and well-being of carers, economic security, information and access, services for carers (for example, emotional support), education and training. The meeting of such needs extends beyond income maintenance benefits and social services provision to equal access to public space and transport, and to anti-discriminatory and anti-

37 EF Kittay 'A feminist public ethic of care meets the new communitarian family policy' (2001) 111 *Ethics* 523.

38 R West 'A right to care' (2004) April/May issue *Boston Review* <http://new.bostonreview.net/BR29.2/west.html> (accessed 15 July 2015).

39 H Arksey & M Morée 'Supporting working carers: Do policies in England and The Netherlands reflect *doulia* rights?' (2008) 16 *Health and Social Care in the Community* 651.

40 Batthyány Dighiero (n 13 above) 13-14.

41 Ministry of Social Development 'The New Zealand carers' Strategy Action Plan for 2014 to 2018' <http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/> (accessed 15 September 2015).

poverty policies. In addition, these kind of policies argue against inequalities in care giving and care receiving.

Williams argues that initiatives of this kind challenge the false dichotomy of carer and cared for, and asserts the fundamental importance of an inclusive citizenship where all those involved in the social processes of care have a voice, particularly those whose voice has historically been marginalised. Therefore, she states that care is not only personal; it is an issue of public and political concern whose social dynamics operate at local, national and transnational levels.<sup>42</sup> The main objective is to support carers, from the communities in which they live, in the planning and provision of the services that they and the person they are caring for need, and to develop policies to help them to combine employment with caring.

However, in many countries, the situation is different because carers' rights remain an invisible issue and public policies are inadequate or non-existent. Africa and Latin America are continental examples of this.

#### 4 Informal carers in Africa

Research examining the needs and situation of informal carers of people with disabilities is not common in the African context. Thus, there is a need for more qualitative studies to provide rich insights into the realities of care.<sup>43</sup>

In South Africa, the White Paper for Social Welfare exhibits a clear preference for family care of persons with disabilities. It recognises that: 'the family is a significant support system in meeting the needs of people with disabilities. Appropriate support must be provided for families involved in care-giving'.<sup>44</sup> The White Paper provides that

home care-givers will be given emotional support in caring for their family members as well as financial support; training in home nursing and how to access the services of organisations providing complementary services, such as psycho-social and spiritual counselling, transport to hospital and home visits.<sup>45</sup>

Moreover, it specifies that women are the key providers of unacknowledged social care to people with disabilities and their needs should be addressed. Malherbe has referred to this policy preference for family care for persons with disabilities and highlighted the fact that its

42 Williams (n 26 above) 487.

43 McNally & Mannan (n 28 above) 1.

44 *White Paper for Social Welfare* (1997) para 1 [http://www.gov.za/sites/www.gov.za/files/White\\_Paper\\_on\\_Social\\_Welfare\\_0.pdf](http://www.gov.za/sites/www.gov.za/files/White_Paper_on_Social_Welfare_0.pdf) (accessed 3 November 2014).

45 *White Paper for Social Welfare* (n 44 above) para 88.

provisions do not translate into sufficient statutory assistance, or into significant practical assistance, to caregivers.<sup>46</sup>

South African social assistance legislation provides for a grant payable to the family caregiver. For both grants, it is the fact that the person with disabilities receives home care that leads to the payment of the grant. On one hand, the care dependency grant is payable to the parent, foster parent or primary caregiver of a child with disabilities. The purpose of the care dependency grant is to assist the parent, foster parent or guardian to care for children with disabilities in their family home. Malherbe explains that the grant discontinues if the child receives 24-hour care in a state funded institution for longer than six months. Thus, it illustrates the link between family homecare of the child with disabilities and the payment of the care dependency grant.<sup>47</sup> On another hand, the *disability grant* is a social grant intended to provide for the basic needs of people with disabilities (adults). In addition, the grant-in-aid is provided as an additional grant to adults who are already receiving the disability grant and it allows them to live at home instead of receiving institutional care. Currently, no grant is payable directly to caregivers while they are providing care for adult family members with disabilities.

As it has been explained in previous sections, support for informal carers goes beyond an economic provision. Other issues such as information and access, services for carers (for example, emotional support), education and training are central. Moreover, a social insurance system that excludes family caregivers or pays them minimum benefits only, cannot be regarded as a reasonable measure to provide access to social security as required by section 27 of the South African Constitution.<sup>48</sup> Thus, states should step in to remove barriers to the realisation of their social security rights.

In Uganda, the National Policy on Disability states that

the family is the basic unit for providing care and support to people with disabilities (PWDs). PWDs should benefit from the family and community care and protection. It is therefore, the responsibility of the parents or caregivers to PWDs to provide food, clothing, housing, love, care, education, health and other basic services that promote and protect the rights of PWDs.

The policy unquestionably places specific duties on informal caregivers. It does so however in the context of acknowledging that caregivers may themselves be the recipients of services. It provides that 'the objectives of this policy are ... (ii) to promote effective friendly service delivery to PWDs and their caregivers; (iii) to ensure that resources for initiatives that

46 Malherbe (n 10 above) 183.

47 Malherbe (n 10 above) 187.

48 Malherbe (n 10 above) 195.

target PWDs and caregivers are mobilised and efficiently utilised'.<sup>49</sup> Strengthening and empowerment of people with disabilities and their caregivers is one of the strategies mentioned by this policy. Moreover, it provides that support will include provision of basic, physical and psychosocial needs of PWDs AND their caregivers.

Objectively, however, the National Policy only addresses the claims of informal carers as one to be addressed by 'soft' rights without providing any specific entitlement or clarity over provision about which services they may receive and what kind of support that should be available. Hartley et al in their analysis of the situation of informal carers of disabled children in Uganda found that informal carers (parents) who participated in their study were coping with their children's disabilities without interaction with national community-based rehabilitation (CBR) programmes. 'Several informants expressed the view that more information would assist them in caring for their children and reducing their own stress levels.'<sup>50</sup> The lack of such support had a negative impact on both the informal caregivers and the carers of children with disabilities. For carers, because they did not receive any support in their task and for children with disabilities, because they did not receive services of quality. Hartley mentions that carers of children with hearing or speech deficits faced particular challenges of the breakdown in communication because of inadequate knowledge in the use of signing and that this was a clear example of the importance of training family caregivers.

Studies about informal caregivers in Kenya indicate that

'because of a lot of care-giving strain and lack of rehabilitation services in the community, carers had to learn new skills to cope with child's disability. They improvise materials for exercises at their homes in order to maintain continuity of therapy'.<sup>51</sup>

In addition, information given was scanty or sometimes non-existent and external support was from almost invariably from non-governmental organisations or charitable organisations. Finally, family caregivers identified poverty as a central impediment to the caring process.

## 5 Informal care in Latin America

In Latin America, despite the progress made on gender equality policies, economic, social and political institutions still operate under the

49 Ministry of Gender, Labour and Social development 'National Policy on Disability in Uganda' January 2006.

50 S Hartley et al 'How do carers of disabled children cope? The Ugandan perspective' (2004) 31 *Child: Care, Health & Development* 174.

51 JK Gona et al 'Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience?' (2011) 37 *Child: Care, Health & Development* 180.

assumption of a sexual division of labour that leads women as primary informal caregivers of people with disabilities. Moreover, there is an absence of policies focused on supporting informal caregivers.

In Colombia, researchers have been addressing this issue and building awareness and there appears to be a general consensus that there is a lack of services to help informal carers on their tasks, and information about the available facilities. This situation may change if the Project of Law 33 of 2009 finally becomes law. This Project recognises family caregivers and establishes their rights; it provides that they will have access to instrumental, emotional and social support. Moreover, caregivers should receive training about the disease or condition of the person in their care, as well as techniques for home care, first aid and medication management. They will have access to health protection and services, and social security. However, currently, this Project has not been enacted as a law. A study conducted to meet the needs of informal carers of people with disabilities revealed that even though the participants considered that there had been some progress in developing public policies related to the needs of people with disabilities, they did not consider that any progress had been made in relation to the needs of informal carers.<sup>52</sup> The study highlighted the severe need for the development of integrated programmes focused on both the welfare of people with disabilities as well as their informal carers.

Argentina and Chile (like South Africa) provide pensions for parents with a son or daughter with a disability and for married couples when one partner has a disability. However, the laws and programmes of these two nations on disability make no provision for the support of caregivers. In most cases, NGO's provide psychological support, information and even training for informal caregivers.

In the case of Chile, the programme 'Chile Crece Contigo'

is an integrated system of social interventions and benefits that aim to provide comprehensive support for children and their families, from the stage of gestation until they enter the school system at four years of age, by providing the tools needed for them to develop their potential to the maximum. Modular implementation of the social-protection system should activate an increasingly wide-ranging welfare system that would include all citizens.<sup>53</sup>

However, this programme is only focused on childhood so it may produce a positive impact on family caregivers of children with disabilities.

Uruguay is in the process of developing a National System of Care (NSC). The programme results from a deep study (in which it is asserted

52 MT Buitrago-Echeverri et al 'Necesidades generales de los cuidadores de las personas en situación de discapacidad' [Overall Requirements in Caregivers of People Experiencing Disability] 12 *Investigación en Enfermería: Imagen y Desarrollo* 60.

53 Batthyány Dighiero (n 13 above) 27.

that civil society was central and all the relevant actors involved had a voice) about the situation of caring in the country and it seeks to address the gender nature of care providing. The NSC is focused on four population groups: childhood, people with disabilities, older people and carers (formal and informal). It provides support and counselling for family caregivers, special permissions at work, training and access to formal care. The NSC is currently in its first phase of implementation and testing.<sup>54</sup> The first action has been to allow people with severe disabilities to choose and hire personal assistants (who cannot be members of their family). It is too soon to make a judgment about the success of this new policy but it definitely implies an important step forward.

In 2010 the strategy of the Costa Rican government (2010-2014) sought to strengthen care options within its social policy, by creating a network of care and development services for children and older adults, and for workers of both sexes and their families. This policy recognised the urgent need to provide care for the most vulnerable sectors and to promote the exercise of a rights-based citizenship. The National Care Network is an institutional network of care services for children and older adults; it is based on an expansion of existing services and also promotes new services and care modalities.<sup>55</sup> However, this programme does not address the issue of people with disabilities and their informal caregivers: the specific needs of this population group have not been included.

Finally, in Ecuador, article 47(9) of its National Constitution recognises that family of people with disabilities have the right to psychological assistance and to receive support in their productive projects. Moreover, article 49 states that family caregivers will be covered by social security and will receive training. Family caregivers receive a grant and the National Plan called *Plan Nacional para el Buen Vivir (PNBV)* provides to support them in their caring role: psychological assistance, health services and training. This Plan is being implemented gradually and its goals must be met by 2017.

## 6 Conclusion

This paper has shown that discussions about caring engage multiple dimensions – principally human rights, social protection, gender and socio-economic inequalities. It has argued that in consequence social protection measures should address the rights of caregivers as a core concern and through normative principles. Informal caregivers require

54 R Aguirre & F Ferrari 'La construcción del sistema de cuidados en el Uruguay: En busca de consensos para una protección social más igualitaria' [Building a system of care in Uruguay: In search of consensus for a more egalitarian social protection] (2014) [http://repositorio.cepal.org/bitstream/handle/11362/36721/S2014269\\_es.pdf?sequence=1](http://repositorio.cepal.org/bitstream/handle/11362/36721/S2014269_es.pdf?sequence=1) (accessed 20 March 2015).

55 Batthyány Dighiero (n 13 above)32.



consideration as the 'subjects' of policies on an equal footing to those they care for and that by acknowledging these factors and by improving their access to social welfare support services, employment support and training – will improve not only the well-being caregivers but also that of the people for whom they care.

According to the CRPD and the social model, disability results from the interaction between persons who have long-term physical, mental, intellectual or sensory impairments and an environment filled with physical, attitudinal, communication and social barriers that hinders their full and effective participation in society on an equal basis with others. Thus, disability is socially constructed by our societies. These are the same societies in which informal care is seen as an exclusively female activity and a private issue inside families. At the same time, the CRPD and the social model provide different principles such as: respect for dignity; individual autonomy; independence; non-discrimination; full and effective participation and inclusion in society; between others. These principles are central in caring relationships however, informal carers need to be trained and supported in order to fulfil with these principles.

Although legislation in Africa and Latin America reflects the view that families have the primary duty to care for family members with disabilities, there is a growing awareness that states should provide protection to these families and support in their care role. Firstly, because care is a gendered activity since women are far more likely than men to be engaged in providing care within home, and to provide care for longer periods of time. Therefore, a neglect of this crucial question creates multiple inequalities that states have the obligation to address. Secondly, because if informal caregivers do not receive support their difficulties may be articulated in the language of 'associative' or indirect discrimination. Thirdly, because the provision of rights and services for caregivers has a positive impact in those they care for.

This paper asserts that in Africa and Latin America, in developing regions, there is a shortage of studies about informal care in terms of national statistics and needs assessment. The dearth of such materials has been an obstacle for this paper and it is evidence of how marginalised this topic is: evidence of the relative invisibility of family caregivers and of how their lives are characterised by conditions of fragility and the lack of resources. In Latin America it is possible to identify a step forward to address these issues. However, the progress made in Chile and Uruguay only impact in a small part of the regional population since the position in the more populated countries (Colombia, Argentina or Brazil) is significantly less. It follows from this analysis that in Africa and Latin

America 'one of the most neglected areas of disability law is the protection of family members providing care to people with disabilities'.<sup>56</sup>

Thinking about reciprocity and yet taking dependency seriously means acknowledging the importance of reciprocating the efforts of those who do the labour of caring. Thus, another (the state) must be available to support and help informal carers. Kittay has chosen to name this notion of reciprocity as 'doulia' which is a term she has adapted from the postpartum caretaker, the 'doula', who assists the mother who has just given birth, not by caring for the infant but by caring for the mother so that the mother can herself care for the infant. From this insight she argues that we have all benefited from the care of another, who has seen us as worthy of an investment of care and attention merely to survive, much less thrive, as we grow into adults. If each is worthy of care, then caregivers, too, deserve care when they are in need.

Even as I care for another, I, too, am worthy of care. This is a notion of fairness and reciprocity that involves at least a third ... This conception provides a theoretical framework that needs specification through explicit programs and policies. It calls for a collective, social responsibility for care, but one that doesn't dilute relationships<sup>57</sup>

between the person who need care and the caregiver. Society has a collective responsibility to support caregivers that must accompany calls for personal responsibility and address gender inequality.

56 Malherbe (n 10 above) 181

57 E Feder Kittay 'A feminist public ethic of care meets the New Communitarian Family Policy' (2001) 111 *Ethics* 532.