

# The role of social workers in addressing caregiver burden in families of persons with disabilities

## Authors

Noreth Muller-Kluits<sup>1</sup>  
Ilze Slabbert<sup>1</sup>

Family caregivers often experience caregiver burden, which includes physical health issues, personal isolation, lack of respite services, employment concerns, financial concerns, poor emotional health, and giving up on personal aspirations.

Disability impacts not only the person with the disability, but also his or her support network, namely friends and family. When a family member has a disability, it is generally the family that provides care. Informal care by a family caregiver is usually seen as a cost-effective way of caring for persons with disabilities. However, this can have critical consequences for caregivers, including post-traumatic stress disorder, emotional distress, caregiver burden, depression, and anxiety.

The aim of this chapter is to explore the burdens experienced by family caregivers in the rehabilitation of persons with disabilities, and to discuss the role of social workers in this process. Family-caregiver experiences

were identified by referring to the literature, with particular reference to a Cape Town study on the subject. The caregiver burdens that emerged included physical health issues, personal isolation, lack of respite services, employment concerns, financial concerns, poor emotional health and giving up on personal aspirations.

Recommendations are made in terms of the role that social workers can play in addressing caregiver burden among family caregivers, and how they can help to address the caregivers' physical, emotional, financial, and social concerns. The social work roles highlighted in the chapter include those of educator, broker and enabler.

## Introduction

---

Parents usually have high aspirations and dreams for their children, but when they discover some anomalies in their new-born child, other emotional experiences can arise,<sup>1</sup> such as guilt based on the belief that they caused the child's disability through genetics, alcohol misuse, or stress. When a person acquires a disability later in life, the adjustment must be made by both the individual and the family.<sup>2</sup> This adjustment is ongoing, with feelings of sorrow alternating with despair and acceptance. Persons with an acquired disability alternate between acknowledging their 'pre-disability' and 'new disability' identity.<sup>3</sup>

Family caregivers often play a central role in the care of persons with disabilities, and the latter depend greatly on the willingness and ability of their families to adopt the unanticipated role of informal caregiving. At the same time, family members experience their own challenges, and need to make their own adjustments, which can impact on the person with disabilities' ability to cope with psychological and physical adaptations.<sup>4</sup> Social workers play an important role in addressing caregiver burden, and in service delivery to persons with disabilities in alignment with the goals of policies such as the White Paper on the Rights of Persons with Disabilities (WPRPD)<sup>5</sup> and the United Nations' Convention on the Rights of Persons with Disabilities (UN CRPD).<sup>6</sup> They do this by facilitating access to necessary resources through interventions such as advice, referral, and advocacy that assist both the person with disability and his/her family<sup>7</sup> with the rehabilitation process. In so doing, social workers can also relieve the caregiver burden often experienced by family members as informal caregivers.

## Policies guiding service delivery to persons with disabilities in South Africa

---

Several international and national policies have worked to establish service delivery for persons with disabilities. Disability inclusion based on the UN CRPD, in conjunction with the 2015 Sustainable Development Goals (SDGs), should now be considered an overarching priority by organisations and individuals committed to improving the quality of life of persons with disabilities.<sup>8</sup>

South Africa ratified the UN CRPD, indicating the government's commitment to protecting the rights of persons with disabilities. The UN CRPD is the first legally binding international convention providing a clear understanding of government responsibilities in addressing the right of people with disabilities to live independently and to be able to participate fully in all aspects of life. The principles of the UN CRPD include, among others, respect

for fundamental dignity and individual autonomy; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities; equal opportunity; and accessibility.<sup>6</sup>

In 2015, The United Nations adopted 17 SDGs based on the principle of 'leaving no one behind'. This principle emphasises a holistic approach to achieving sustainable development for all.<sup>9,10</sup> In contrast to the Millennium Development Goals (MDGs), which did not mention persons with disabilities, the SDGs emphasise that people who are vulnerable must be empowered, including persons with disabilities, of whom more than 80% live in poverty.<sup>9</sup>

In 2016, the Department of Social Development launched the White Paper on the Rights of Persons with Disabilities (WPRPD),<sup>5</sup> which modernises South Africa's Integrated National Disability Strategy White Paper<sup>11</sup> and integrates the obligations of the UN CRPD<sup>6</sup> and the Continental Plan of Action for the African Decade of Persons with Disabilities,<sup>12</sup> along with South Africa's legislation, policy frameworks and the National Development Plan (NDP) 2030.<sup>13</sup> The 2016 WPRPD supports mainstreaming of the rights of persons with disabilities and provides clear guidance on policy development. Norms and standards are stipulated for removing discriminatory barriers for persons with disabilities and a framework is provided for the responsibilities and accountabilities of the different stakeholders. Once the WPRPD is implemented, persons with disabilities should be given the opportunity to enjoy their full political, human, social and economic rights to participate fully and equally in mainstream social and economic life. In addition, they should be given the right to live and work in safe and accessible environments free from discrimination, harassment and persecution.<sup>5</sup>

In 2017, the Rehabilitation 2030: A Call for Action meeting noted that rehabilitation is a vital objective in the World Health Organization (WHO) Global Disability Action Plan 2021. However, under the sustainable development agenda, rehabilitation services need to be brought into a broader context to achieve SDG goal 3, namely to "[e]nsure healthy lives and promote well-being for all at all ages".<sup>14</sup>

## Social work and disability

---

Most people will experience a form of impairment or disability in their lifetime – either temporary or permanent.<sup>15</sup> Various forms of impairment can occur at any given moment, examples being a baby born with Down Syndrome, a soldier losing his leg at war, or a person suffering a stroke resulting in paralysis on one side of the body. A need for rehabilitation will occur, regardless of the condition. The World Report on Disability<sup>15</sup> defines rehabilitation as "a set of measures that assist individuals who experience ... disability to achieve and maintain optimal functioning in interaction with their environments".

In South Africa, most stroke survivors and other persons with disabilities will receive rehabilitation within the government sector;<sup>16</sup> however, rehabilitation is not always prioritised within the sector.<sup>17</sup> Non-governmental organisations (NGOs) have frequently stepped in where government services have failed to provide for communities' unique needs. They have the potential to innovate and specialise, while still partnering with governments to deliver services,<sup>18</sup> delivering services for a small or no fee. In communities where resources are limited, the only access that persons with disabilities may have to services such as schooling and employment may be through NGOs.<sup>19,20</sup>

Social work support to persons with disabilities can refer to the reconstruction and aftercare services of social work intervention, focused on reintegration and support services to enhance self-reliance and optimal social functioning.<sup>21</sup> This is aligned with WPRPD<sup>5</sup> pillars 3 and 4, i.e. 'Supporting Sustainable Integrated Community Life' and 'Promoting and Supporting Empowerment of Persons with Disabilities'. Collaboration between social workers and persons with disabilities (and their families) can assist in promoting social inclusion and community living,<sup>22</sup> which is what the WPRPD aims to work towards, aligned with NDP 2030 and the UN CRPD.

### Social work: understanding disability in context

Social workers have worked in the disability sector at micro and macro levels since the beginning of their profession. Further, they are responsible for promoting client/consumer participation at case level, agency level, and policy level, and for incorporating persons with disabilities as a critical part of the profession.<sup>23</sup>

A study of adults with acquired physical disability in South Africa<sup>24</sup> found that they experienced the stages of grief identified by Ross and Deverell,<sup>25</sup> including shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance. These stages correlate with the stages of grief identified by Kübler-Ross.<sup>26</sup> This correlation should be noted, because when a disability occurs in a family, an adjustment needs to be made, and often the pre-disability life is grieved. Social workers play an important role in assisting persons with disabilities and their families in working through these feelings in the different stages. Dorsett<sup>7</sup> noted that social workers play a further role within the rehabilitation team in that they provide information and reassurance, help to explore meaning and appraisals, and assist with the development of problem-solving skills.

Pivotal roles of the social worker in the delivery of services to persons with disabilities and their families include (but are not limited to) the roles of educator, broker, and enabler.

- As an educator, the social worker provides information, education, and preventive care.<sup>27,28</sup> Besides educating the community on how to prevent certain disabilities, the social worker can assist families as an educator when the latter have to take on the role of caregiver. As discussed in this chapter, many family caregivers feel

overwhelmed by the task of caregiver. The social worker can provide the family with the relevant knowledge of services available in the community context to assist them with this.

- As a broker, the social worker mediates, defends, and advocates on behalf of the client and serves as a case manager within a multi-disciplinary rehabilitation team.<sup>28-30</sup> Interdisciplinary teams that include social workers have been reported to pay increased attention to patients' wishes<sup>31</sup> and to improve patient and family involvement in ethical decision-making processes in their healthcare situations.<sup>32</sup> Further, social workers can assist with caregiver burden by acting as mediators between the family, the person with disability, and other health professionals in the rehabilitation process, ensuring that the concerns of families are also heard, understood and acknowledged.
- As an enabler, the social worker facilitates client systems to be more independent. This promotes interaction between individuals and the environment as clients are empowered to make use of resources in the community.<sup>33</sup> Relieving caregiver burden refers not only to supporting the family in the rehabilitation process, but also to empowering them to be able to continue the role as self-sufficiently as possible. This can also be done by empowering the person with disability to be a participant within the community, potentially minimising his or her dependence on family for caregiving. This in turn will require advocating for the rights of persons with disabilities in the community.

Social workers and family caregivers often work together in the rehabilitation of persons with disabilities, and it is therefore important to look at the family caregivers' role and experience.

## Families as caregivers of persons with disabilities in South Africa

Most people with intellectual and developmental disabilities live with their families.<sup>34</sup> Family caregivers often provide ongoing care, which often requires exceptional resources of a physical, emotional, social, and financial nature.<sup>35</sup>

The shift of rehabilitation services from being institutionalised to being provided at home has made the role of family caregivers pivotal in providing social and emotional support for persons with a physical disability.<sup>36</sup> Besides physical care of the person with a disability, family caregivers must also coordinate multifaceted interventions while still balancing the needs of other family members.<sup>35</sup> These interventions include helping their dependent family members with daily tasks, making appointments, managing finances and medication, organising socialisation and recreational activities, and supervising and assisting their family member with bathing, meal preparation, and feeding.<sup>37</sup>

## Services used by family caregivers

According to Bronfenbrenner's ecological perspective,<sup>38</sup> family caregivers make use of different services on different levels. In his model, the microsystem is the immediate, most intimate and closest system to an individual.<sup>39</sup> The mesosystem refers to interconnections with two or more influences outside the immediate environment, such as school and peer influences. The exosystem is the community context, which may not be directly experienced by the individual but that may influence the elements of the microsystem, while the macrosystem refers to the wider social, cultural, and legal context that encompasses all the other systems.<sup>40</sup>

In terms of this perspective, family caregivers make use of familial support, e.g. parents, spouses, life partners and their children (the microsystem).<sup>41</sup> Support at this level helps family caregivers cope and enables them to take better care of the family member with a physical disability.<sup>41</sup> Family caregivers also get a form of support from extended family members, friends, professionals, and other community members (the mesosystem).<sup>41,42</sup> Further, it was found that family caregivers of persons with physical disabilities make use of community services (exosystem) to assist them with their caregiver role. These services include social work organisations, disability organisations, public health clinics, public hospitals, rehabilitation centres, tertiary hospitals, private hospitals, churches, special needs schools, mainstream schools with special aids, language centres, after-school training institutions, financial aid trusts, community transport services, horse-riding centres, and guide-dog services.<sup>41</sup> At a macrosystem level, family caregivers make use of the South African healthcare system (both public and private), the education system, and disability benefits such as social grants.<sup>41</sup>

## Caregiver burden among family caregivers

A person's disability is a triadic experience, which includes the person who has the disability, the family that is affected by it, and the external environment affecting the disability. Informal care by a family caregiver is usually seen as a cost-effective way of caring for persons with disabilities. However, it can have difficult consequences for caregivers, including post-traumatic stress disorder, emotional distress, caregiver burden, depression, and anxiety.<sup>43,44</sup> These caregivers require services to support them in their caregiver role.

Caregiver burden is an umbrella term used to describe the physical, emotional and financial experiences of a caregiver in response to the challenges and demands of providing help for a person with a disability.<sup>45,46</sup> Their experience often manifests in feelings of responsibility, uncertainty about the person with disability's needs, constant worries, restrictions on the caregivers' social life, and the perception that patients rely exclusively on their care,<sup>47</sup> which often leads to negative outcomes. It is important to analyse the effects of caregiving as disability affects the entire family, not just the person who is disabled.<sup>48</sup>

## Family caregiver experiences

A Cape Town study of family caregivers of persons with physical disabilities<sup>41,49</sup> found that family caregivers experience various degrees of caregiver burden, including physical, emotional, financial, and social. The study included 20 family caregivers of persons with different physical disabilities (both congenital and acquired) and included mothers, fathers and siblings as caregivers. A contributing factor to the caregiver burden experienced was long-term care for the person with disability, which led to other issues such as worrying about the future of the person with a disability, and limitations on the family caregiver in terms of finding employment opportunities. Long-term care led to greater financial strain and affected the family caregiver's physical and emotional health.

### Physical health issues

Taking responsibility for lifelong caregiving of a person with a disability may increase stress and impact the mental and physical health of family caregivers.<sup>50</sup> Caregivers tend to neglect their own health needs as they focus on the needs of the person with a disability.<sup>35</sup> Many reported chronic fatigue, sleep deprivation, chronic physical ailments, shoulder pain, and lower back pain.<sup>35,41</sup> Specifically, as the person with disabilities got older and gained weight, the process of physically assisting them was heavy on caregivers' backs.<sup>41</sup>

### Personal isolation

Isolation and loneliness indicate a need for social connection.<sup>51</sup> The added responsibility of taking care of a person with disability means that family caregivers are not able to go out as much as before. This can put them at risk of feeling personal isolation if they do not have other means of support.<sup>41</sup> In this context, a feeling of isolation is two-fold: feeling alone in not being able to socialise, and feeling 'alone' in one's circumstance, meaning without adequate support.

### Lack of respite services

Caregivers of people with physical disabilities often feel that they need more time for themselves.<sup>41,52</sup> A family caregiver stated: "It's difficult. The thing is you don't have your time. I don't have 'my time' ... I can never just go out and have coffee somewhere. Even if I go somewhere, I feel rushed".<sup>45</sup> It is also common for caregivers to use respite hours to care for other family members rather than to restore themselves.<sup>35</sup>

### Employment concerns

Due to the time-consuming responsibility of taking care of a family member with a disability, family caregivers may have to reduce or completely resign from paid employment, leading to financial challenges.<sup>15</sup> In a Cape Town study of family caregivers of persons with physical disabilities, half of the participants were not employed at all. Some of them were unemployed due to the caregiver responsibility they had to take on, as they were unable to make any other provisions in caring for the person with disability due to the lack of long-term care, recreational activities/groups, or

disability-friendly employment, which would have allowed for respite time and/or employment for the caregiver. This situation could lead to financial challenges such as a loss of salary and benefits, loss of promotional and training opportunities, and a reduction in retirement savings.<sup>41</sup> In the words of one mother of a person with spinal cord injury: “I had to give up my job to take care of him. It was a big sacrifice because it was an extra income that fell away”.<sup>41</sup>

### Financial concerns

As discussed, lack of employment for both the caregiver and the person with a disability can put extra financial strain on the family. Caring for a person with a physical disability sometimes requires additional spending, which may continue over a lifetime. In such cases, the need could arise for money to be put aside in a trust fund to ensure care of the person with a disability should the family caregiver pass away.<sup>2</sup> Family caregivers have indicated that some of the financial issues they face include medical service and equipment expenses, school-related expenses, and specialised transport expenses.<sup>2,41</sup> Financial struggles can lead to the additional issue of not being able to access certain services. Parents from a lower socio-economic background who might not be able to pay for private (special) education, will need to make use of public medical facilities and public transport, and will most likely not be able to put money away in a trust fund for the child.<sup>2</sup> The sister of a person with cerebral palsy, who had to take over the caregiver role after her parents passed away, expressed her situation this way: “My sister was in a school but only for two months ... financially we could not keep it up”.<sup>41</sup>

### Poor emotional health

Emotional health issues can start with the initial reaction that family caregivers have to their new caregiving role,

but can also arise from long-term caring for a family member with a (physical) disability. In many cases, initial family-caregiver reactions are negative and related to grief. Grief refers to the process whereby a person can separate him or herself from someone or something that has been lost.<sup>25</sup> The five stages of grief identified by Kübler-Ross<sup>26</sup> have been adapted to nine phases, namely shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance.<sup>25</sup> A mother of two children with disabilities (deaf and blind respectively), said: “When my child went to school, I actually had like a part-time depression. I had a breakdown. And for the first time in my life I had to go onto tranquilisers. And I am not one of those people”.<sup>41</sup>

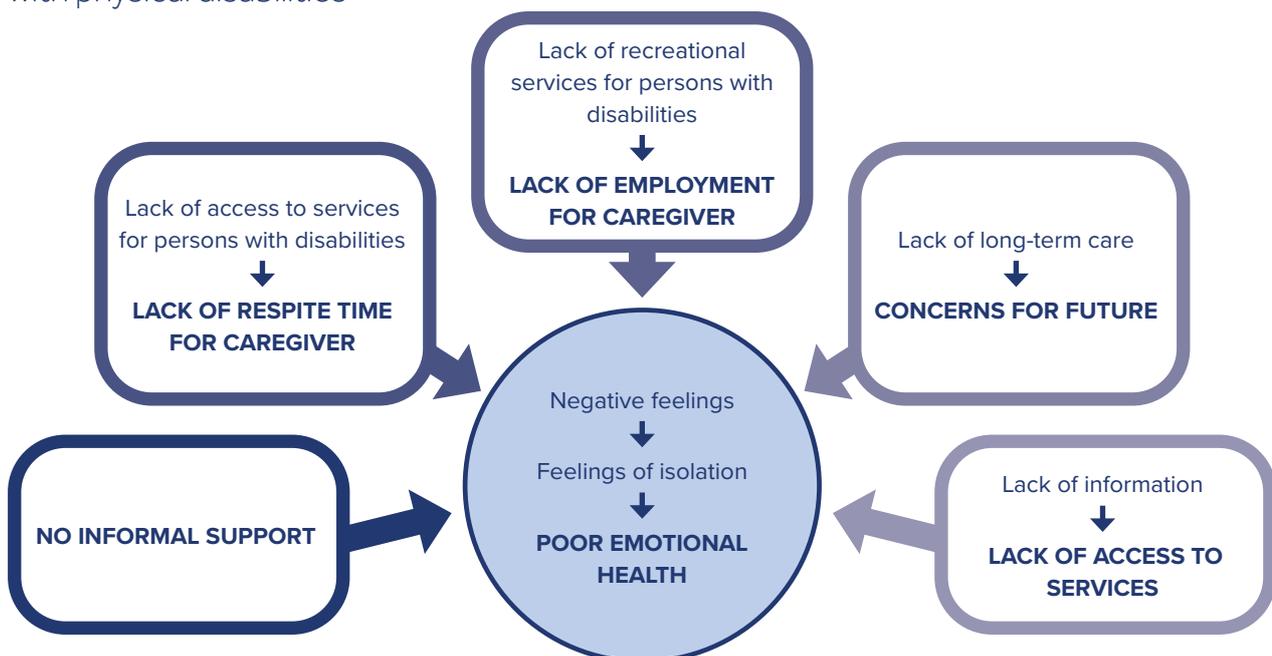
### Giving up on personal dreams (caregiver)

Some (sibling) family caregivers have indicated how their caregiving role meant that they had to give up on their own dreams and aspirations. They expressed how they still struggled to come to terms with the situation,<sup>45</sup> as evident in the following words: “It put a responsibility on my shoulders for the rest of my life. I will never do what I really want to do”.<sup>41</sup> The act of giving up on personal dreams and aspirations can lead to family caregivers feeling ‘inward anger’ and depression about their circumstances.<sup>25</sup>

### Correlation between caregiver experience and emotional health

In examining the findings of the Cape Town study of family caregivers,<sup>41</sup> a few recurring scenarios were observed. There was a clear correlation between lack of services or support and negative emotional health. The different scenarios are illustrated in Figure 1 below:

Figure 1: Experiences leading to poor emotional health among family caregivers of persons with physical disabilities



Source: Muller-Kluits, 2017.<sup>41</sup>

In contrast, the study<sup>41</sup> found that in cases with significant support, the outcome was positive. The study also found that once family caregivers have more respite time, they have more opportunity to find employment. Employment opportunities for family caregivers assist with financial concerns, which can reduce poor emotional health and potentially support positive experiences and acceptance of the caregiver role.

### Addressing family caregiver burden: the social worker's role

Social workers are important role players in delivering services to people with disabilities. For instance, a South African study on disability and poverty<sup>53</sup> found that 31% of persons with disabilities (and their families) identified a social worker as one of the main sources of social support available to them. They also indicated that they were more aware of social workers than of other service providers such as home-based carers, community rehabilitation workers and rehabilitation therapists.<sup>54</sup>

According to the WPRPD, four pillars inform and guide the mainstream agenda for persons with disabilities, namely rights, empowerment, equality, and results.<sup>5</sup> Social workers have an obligation to assist persons with disabilities and their families with full integration into society, as aligned with policies such as the WPRPD. This involves assistance with respite services and employment opportunities which will, in turn, relieve the caregiver burden of family caregivers.

Social workers play a vital role in the multidisciplinary care model of rehabilitation. They do psychosocial assessments, psychosocial counselling, discharge planning, case management, and psychosocial health education,<sup>55</sup> using their knowledge of theories such as the social model, the biopsychosocial perspective, and the ecological perspective in understanding how the individual interacts with his/her environment. Specifically, the pivotal social-work roles of broker, enabler and educator in service delivery to persons with disabilities (discussed earlier), can assist with caregiver burden.

## Recommendations

---

- Lack of respite time or lack of employment opportunities for family caregivers due to their strenuous caregiver role, can be minimised directly with increased integration of persons with disabilities into society. This could be done through recreational activities and disability-friendly employment for persons with disabilities.
- Familiarisation with the WPRPD should be a key component in addressing caregiver burden. In fulfilling their triple role (educator, broker, enabler), social workers can utilise the WPRPD to plan service delivery to persons with disabilities and their families, specifically

via pillars 3 and 4, which focus on integrating persons with disabilities back into the community.

- Advocacy on the specific role of social work in the disability sector would also increase awareness of support available to family caregivers to relieve some of the caregiver burden.
- As mentioned earlier, social workers have a vital role to play in the multi-disciplinary team of service providers. Their holistic consideration of the individual in context, along with the role they play within the community, are just some aspects that could be advocated and strengthened in the disability sector.
- Finally, when planning service delivery or policy development for persons with disabilities and their families in order to address caregiver burden through social integration, it is important to use a bottom-up approach in which the service users are consulted on their specific needs. This approach could extend further, with service users serving as lay experts and peer support for others.

## Conclusion

---

As mentioned earlier, persons with disabilities depend greatly on the willingness and ability of their families to adopt unexpected informal caregiving roles. Cohen and Napolitano<sup>56</sup> claim that a family's response to disability has a powerful influence on the individual; they refer to the actor, Christopher Reeve, who was paralysed after a horse-riding accident and who noted the importance of family support during his rehabilitation. However, many family caregivers do experience caregiver burden as a result of the challenges they face in their new, often unanticipated, role as an informal rehabilitation worker to their family member with a disability. Social workers' understanding of the social environment and their triple role as educators, brokers and enablers can assist with the rehabilitation process. Collaboration between social workers and persons with disabilities (and their families) can help to promote social inclusion and community living,<sup>22</sup> which is what the WPRPD aims to work towards, aligned with NDP 2030 and the UN CRPD. Social workers, therefore, play an important role in assisting family caregivers in the rehabilitation of persons with disabilities.

## References

---

1. Gull M, Nizami N. Comparative study of hope and psychological well-being among the parents of physically and intellectually disabled children. *Int J Modern Soc Sci*. 2015;4(42):143-52.
2. Trollope AM. The impact of socio-economic factors on raising a child with mental disability in the North West of Pretoria. Master of Social Work (Health Care) mini thesis. Pretoria: University of Pretoria; 2013. URL: [https://repository.up.ac.za/bitstream/handle/2263/46182/Trollope\\_Impact\\_2014.pdf?sequence=1&isAllowed=y](https://repository.up.ac.za/bitstream/handle/2263/46182/Trollope_Impact_2014.pdf?sequence=1&isAllowed=y).
3. Kendall E, Buys N. An integrated model of psychosocial adjustment following acquired disability. *J Rehabil*. 1998;64(3):16-20.
4. Migerode F, Maes B, Buysse A, Brondeel R. Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience. *J Dev Phys Disabil*. 2012;24(5):487-503.
5. Department of Social Development. White Paper on the Rights of Persons with Disabilities. Government Notice No. 230, Government Gazette No. 39792; 9 March 2016. URL: [https://www.gov.za/sites/default/files/gcis\\_document/201603/39792gon230.pdf](https://www.gov.za/sites/default/files/gcis_document/201603/39792gon230.pdf).
6. United Nations General Assembly. Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, A/RES/61/106; 24 January 2007. URL: <https://www.refworld.org/docid/45f973632.html>.
7. Dorsett P. The importance of hope in coping with severe acquired disability. *Aust J Soc Issues*. 2010;63(1):83-102.
8. Mittler P. UN Disability Convention and Millennium Development Goals. *J Policy Pract Intellect Disabil*. 2015;12:79-89.
9. United Nations General Assembly. Transforming our world: the 2030 Agenda for Sustainable Development, A/RES/70/1; 21 October 2015. URL: <https://www.refworld.org/docid/57b6e3e44.html>.
10. Steenkamp L. How the South African government is failing people with disabilities. South African Human Rights Commission; 21 November 2017. URL: <https://www.sahrc.org.za/index.php/sahrc-media/news/item/1020-how-the-south-african-government-is-failing-people-with-disabilities>.
11. Office of the President. Integrated National Disability Strategy White Paper; November 1997. URL: <https://www.gov.za/documents/integrated-national-disability-strategy-white-paper>.
12. African Union Commission: Department of Social Affairs. Continental Plan of Action for the African Decade of Persons with Disabilities 2010-2019. Addis Ababa: AUC; 18 April 2013. URL: [https://au.int/sites/default/files/pages/32900-file-cpoa\\_handbook.\\_audp.english\\_-\\_copy.pdf](https://au.int/sites/default/files/pages/32900-file-cpoa_handbook._audp.english_-_copy.pdf).
13. National Planning Commission. National Development Plan 2030. Pretoria: The Presidency; 2011. URL: <https://www.poa.gov.za/news/Documents/NPC%20National%20Development%20Plan%20Vision%202030%20-lo-res.pdf>.
14. World Health Organization. Rehabilitation 2030: a call for action. Geneva: WHO; 2017. URL: [https://www.who.int/disabilities/care/Rehab2030MeetingReport\\_plain\\_text\\_version.pdf](https://www.who.int/disabilities/care/Rehab2030MeetingReport_plain_text_version.pdf).
15. World Health Organization and World Bank. World report on disability. Geneva: WHO; 2011. URL: [https://www.who.int/disabilities/world\\_report/2011/report.pdf](https://www.who.int/disabilities/world_report/2011/report.pdf).
16. Minister of Health. National Health Insurance in South Africa: Policy Paper; 12 August 2011. URL: [https://www.gov.za/sites/default/files/gcis\\_document/201409/nationalhealthinsurance2.pdf](https://www.gov.za/sites/default/files/gcis_document/201409/nationalhealthinsurance2.pdf).
17. Philpott S. Budgeting for children with disabilities in South Africa. Commissioned by the Children's Budget Unit of IDASA and the South African Federal Council on Disability. Cape Town: Institute for Democratic Alternatives in South Africa; 2004. [Referenced in: The African Child Policy Forum. Children with disabilities in South Africa: The hidden reality. Addis Ababa: The African Child Policy Forum; 2011.] URL: [http://uhambofoundation.org.za/new\\_wp/wp-content/uploads/2016/06/2011-ACPF-Children-with-disabilities-in-South-Africa-The-hidden-reality.pdf](http://uhambofoundation.org.za/new_wp/wp-content/uploads/2016/06/2011-ACPF-Children-with-disabilities-in-South-Africa-The-hidden-reality.pdf)].
18. Singh S. Implementing rehabilitation programmes: Briefing to the joint monitoring committee on improvement of quality of life and status of children, youth and persons with disabilities. South African National Department of Health; 2008. URL: <https://pmg.org.za/committee-meeting/9222/>.
19. Mall S, Swartz L. Perceptions of educators of deaf and hard-of-hearing adolescents of HIV risk factors for these youths. *Afr J AIDS Res*. 2012;11(4):343-8.
20. Mall S, Swartz L. Sexuality, disability and human rights: Strengthening healthcare for disabled people. *S Afr Med J*. 2012;102(10):792-3.
21. Department of Social Development. Integrated Service Delivery Model. Pretoria: DSD; 2006. URL: <https://www.gov.za/documents/service-delivery-model-developmental-social-welfare-services>.
22. Ministry of Social and Family Development. Disability Social Work Symposium. 18 May 2018. Singapore: Rainbow Centre; 2018.
23. Mackelprang RW. Disability: Overview. In: *Encyclopedia of Social Work*; 2013: p. 1-15. URL: [https://oxfordre.com/socialwork/oso/viewentry/10.1093\\$002facrefore\\$002f9780199975839.001.0001\\$002facrefore-9780199975839-e-541;jsessionid=0BBE7CF7D6B8055457D6F949C93EB26C](https://oxfordre.com/socialwork/oso/viewentry/10.1093$002facrefore$002f9780199975839.001.0001$002facrefore-9780199975839-e-541;jsessionid=0BBE7CF7D6B8055457D6F949C93EB26C).
24. Muller-Kluis N. Experiences of adults with acquired physical disabilities of social work support in a South African context. Doctor of Philosophy (Social Work) thesis. Stellenbosch: Stellenbosch University; 2020.

25. Ross E, Deverell A. Health, illness and disability: Psychosocial approaches. 2nd ed. Pretoria: Van Schaik Publishers; 2010.
26. Kübler-Ross E. On death and dying. *JAMA*. 1972; 221(2):174-9.
27. Kittay EF, Jennings B, Wasunna AA. Dependency, difference and the global ethic of long term care. *J Polit Philos*. 2005;13(4):443-69.
28. Miley KK, O'Melia M, Dubois BI. Generalist social work practice: an empowering approach. London: Allyn and Bacon; 1995.
29. Sapežinskienė L. Home-based rehabilitation: roles of a social worker from the viewpoint of disabled people. Kaunas: Vytauto Didžiojo Universitetas; 2000. [Referenced in: Sapežinskiene L, Svediene L, Guscinskiene J. The role of social worker in a team of rehabilitation: methodological approach. *Medicina (Kaunas)*. 2003;39(9):879-83.]
30. Sapežinskiene L, Svediene L, Guscinskiene J. The role of social worker in a team of rehabilitation: methodological approach. *Medicina (Kaunas)*. 2003;39(9):879-83.
31. Black R, Collyer M, Skeldon R, Waddington C. A survey of the illegally resident population in detention in the UK. Home Office Online Report 20/05. URL: [https://www.researchgate.net/publication/265115805\\_A\\_survey\\_of\\_the\\_illegally\\_resident\\_population\\_in\\_detention\\_in\\_the\\_UK](https://www.researchgate.net/publication/265115805_A_survey_of_the_illegally_resident_population_in_detention_in_the_UK).
32. Joseph MV, Conrad AP. Social work influence on interdisciplinary ethical decision making in health care settings. *Health Soc Work*. 1989;14(1):22-30.
33. Engelbrecht LK. Introduction to social work. Wellington: Lanzo; 1999.
34. Simpican SC, Leader G, Kosciulek J, Leahy M. Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Res Dev Disabil*. 2015;38:18-29.
35. Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: Caregiver perspectives. *Child Care Health Dev*. 2007;33(2):180-7.
36. Antle BJ, Mills W, Steele C, Kalnins I, Rossen B. An exploratory study of parents' approaches to health promotion in families of adolescents with physical disabilities. *Child Care Health Dev*. 2008;34(2):185-93.
37. Broodryk M. Traumatic brain injury caregivers' experiences: An exploratory study in the Western Cape. Master of Arts (Psychology) thesis. Stellenbosch: Stellenbosch University; 2014. URL: <http://hdl.handle.net/10019.1/95806>.
38. Bronfenbrenner U. The ecology of human development: Experiments by nature and design. Cambridge: Harvard University Press; 1979.
39. Parker L. An ecological perspective of adolescents' need for support during pregnancy. Masters of Social Work thesis. Stellenbosch: Stellenbosch University; 2011. URL: <https://scholar.sun.ac.za/handle/10019.1/6526?show=full>.
40. Xu Y, Filler J. Facilitating family involvement and support for inclusive education. *The School Community Journal*. 2008;18(2):53-72.
41. Muller-Kluits N. Experiences of family caregivers of persons with physical disabilities. Master of Social Work thesis. Stellenbosch: Stellenbosch University; 2017. URL: <http://hdl.handle.net/10019.1/102919>.
42. Edmonds SC. Behind the numbers: Welfare reform from an ecological perspective. *Int J Public Admin*. 2003;26(7):753-71.
43. Elliott TR, Pezent GD. Family caregivers of older persons in rehabilitation. *NeuroRehabilitation*. 2008;23(5):439-46.
44. Kress JP, Herridge MS. Medical and economic implications of physical disability of survivorship. *Semin Respir Crit Care Med*. 2012;33(4):339-47.
45. Jeong YG, Myong JP, Koo JW. The modifying role of caregiver burden on predictors of quality of life of caregivers of hospitalized chronic stroke patients. *Disabil Health J*. 2015;8(4):619-25.
46. Pangalila RF, Van Den Bos GAM, Stam HJ, et al. Subjective caregiver burden of parents of adults with Duchenne muscular dystrophy. *Disabil Rehabil*. 2012;34(12):988-96.
47. Scholte OP, Reimer WJM, De Haan RJ, Rijnders PT, Limburg M, Van Den Bos GAM. The burden of caregiving in partners of long-term stroke survivors. *Stroke*. 1998;29:1605-11.
48. Goldner M, Drentea P. Caring for the disabled: Applying different theoretical perspectives to understand racial and ethnic variations among families. *Marriage Fam Rev*. 2009;45(5):499-518.
49. Muller-Kluits N, Slabbert I. Caregiver burden as depicted by family caregivers of persons with physical disabilities. *Social Work (Stellenbosch)*. 2018;54(4):493.
50. Reichman NE, Corman H, Noonan K. Impact of child disability on the family. *Matern Child Health J*. 2008;12(6):679-83.
51. Pelentsov LJ, Laws TA, Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disabil Health J*. 2015;8(4):475-91.
52. Dingana CJN. What are the needs of people with physical disabilities in the district of Butterworth and how accessible are available resources to them? Master of Science: Medical Sciences (Rehabilitation) thesis. Stellenbosch: Stellenbosch University; 2012. URL: <http://hdl.handle.net/10019.1/20379>.

53. Graham L, Selipsky L, Moodley J, Maina J, Rowland W, and the Centre for Social Development in Africa. Understanding poverty and disability in Johannesburg. Johannesburg: University of Johannesburg; 2010. URL: <https://www.uj.ac.za/faculties/humanities/csda/Documents/Poverty%20and%20Disability%20Report.pdf>.
54. Lorenzo T, Cramm JM. Access to livelihood assets among youth with and without disabilities in South Africa: Implications for health professional education. S Afr Med J. 2012;102(6):578.
55. Springer DW, Casey KA. Rehabilitation. Subject: Disabilities, Health Care and Illness, Social Justice and Human Rights. In: Encyclopedia of Social Work; June 2013. URL: <https://oxfordre.com/socialwork/view/10.1093/acrefore/9780199975839.001.0001/acrefore-9780199975839-e-340>.
56. Cohen C, Napolitano D. Adjustment to disability. J Soc Work Disabil Rehabil. 2007;6(1-2):135-55.