

OLDER PERSONS AND COMMUNITY CARE IN SOUTH AFRICA

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 **FAMILY
CAREGIVING**
Care Of Older Persons in Southern Africa

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Introduction

The Older Persons Act (2006) emphasises family- and community-based care. One of the main objectives of the Act, outlined in section 2 (c) is to:

shift the emphasis from institutional care to community-based care in order to ensure that an older person remains in his or her home within the community for as long as possible

Given this mandate, the Family Caregiving of Older Persons programme seeks to understand how family and community-based care is experienced in communities.

Our recent analysis on Funding Elder Care Provision in South Africa indicated a 13 percent decrease in provincial spending on family-and community-based care.



In this report, we get a sense of what Department of Social Development spending on older persons means in the everyday as family caregivers, care workers and older persons share their experiences of family-and community-based care. We foreground the voices of older persons in line with The South African Older Persons Forum [1] which serves as a voice of older persons when engaging with government.

[1] South African Older Persons Forum (SAOPF): <https://saopf.org.za/>

South Africa has one of the larger, older and fastest growing populations of older persons in the African region.

5.6 million older persons in South Africa

(9 % of the population)

73%

3.8 million people (73%) receive an older persons grant



The main form of state support for older persons is the Older Persons' Grant, which 3,8 million persons aged 60 years and older receive. Men and women who reach age 60 are likely to live 17- and 20-years additional years respectively. Many older persons suffer from multiple health conditions, such as diabetes and hypertension. The care implications that various conditions bring are significant. Many older persons have difficulty with walking, accessing public transport, remembering things, or learning a new task. Estimates on the number of older persons living in community settings in South Africa who need assistance with everyday activities such as eating, walking, washing etc. varies but is estimated to be at least 40 percent. Managing the conditions, disabilities and caring for older persons happens within families and communities.

To support families and community-based care the state provides subsidies for both persons attending community service centres and for older persons who access beds at residential care homes. Currently approx. 80 000 older persons

receive some care support at a community service centre and 18,011 people receive subsidies in state-subsidised care homes. Many older persons do not have access to a service centre near them and many older persons are not able to access the service centre in their community due to disabilities and having high care needs. In this report we hear from older persons and caregivers about the challenges in supporting family and community based care of older persons across different contexts.

The fora were facilitated by members of the Family Caregiving of Older Persons Programme and members of the partnering organisation and held in the local language of the community. The fora were only lightly structured, so that the focus was on the concerns of the older persons. Following a short introduction of the aim of the fora, there were four key areas of discussion which focussed on 1) experiences of family care, 2) challenges of family care, 3) support services available and 4) support services needed.

In 2023, between March and August, the Family Caregiving of Older Persons Programme, in collaboration with its partners hosted a series of six fora in the Western Cape and KwaZulu-Natal. In reflecting on 'Family Care of Older Persons', the purpose of the fora was to gain a deeper understanding of how family caregiving is experienced in communities [2]. The fora were designed to create a space for a conversation at the local level for older persons, family caregivers and professionals engaged in care of older persons. Participants reflected and considered the needs, challenges and services that support older persons. Through this process we could provide evidence on how families interact with services, policies, and infrastructures of care at the community level.



In some fora, ideas were captured on A1 posters, in other fora, extensive notes were taken and shared with the partnering organisation.

[2] In using the concept of community, we recognise that it is not always clear what exactly is meant by 'the community' and how we can know who is part of the community. We also recognise that the conditions of certain groups within a community are not identical and call for more research to be undertaken at the local level to generate a better understanding of care concerns and priorities.



if we are not attentive to the needs of others, then we cannot possibly address those needs

The intention is to share this report with all attendees of the fora. As well as this report, individual reports have been made for each community which presents the key themes identified by each of the fora.

The aim of this report is to present an overview of the various issues that were raised in the fora. Members of the community were supported in attending the fora through the provision of transport costs and lunch was provided. There was great interest, attendance and support for the fora which may indicate the gap in such spaces where older persons and caregivers (paid and unpaid) get to discuss and share their opinions about the services and challenges encountered in supporting older persons. In many instances the fora acted as a starting point for greater community awareness and involvement in discussing and addressing such challenges. In areas where there are no service centres for older persons, these fora acted as the first meeting between home-based carers, family caregivers, community health care workers. In some instances, the fora were followed up with subsequent community meetings, especially as interest grew and more stakeholders attended.

***Tronto J (1993) Moral Boundaries:
A Political Argument for an Ethics of Care.
London: Routledge.***

The fora also acted as the start of mobilising and connecting people in the community whereby information, resources and support could be shared via a dedicated WhatsApp group.

There are key issues that connect family caregiving of older persons across the different communities. There was agreement that family caring for older persons is critical yet challenging and that there are ways in which services could support family caregiving better. The report will present an overview of the main points raised at the fora and is divided into three chapters that look at both the experiences and challenges and ideas for improving support services for family caregiving. The report opens with a brief overview of the findings and the recommendations regarding adjustments to policies and services that can better support family caregiving. In this report, we draw on the words, experiences, and opinions of the attendees.

Reflections from NPO Partners



TAFTA

Wentworth Older Person's Forum

Hosting the Family Care Forum was facilitated by two factors: 1) The meetings between the reps from Tafta and reps from the Family Care Programme helped to clarify the logistical arrangements and programme format needed for the best outcomes. Guidance provided by Prof Moore and Dr Kelly were helpful. 2) Tafta's infrastructure and networks helped to secure an accessible and spacious venue, access a good caterer in the community and ensure that a good representation of older persons, caregivers, organisation's dealing with older persons and government officials were present at the Forum. We anticipated 30 attendees but ended up with approx. 45 people in attendance.

Due to the high number of participants in attendance it's important to have multiple people who could facilitate the discussions. The need for a robust team is critical. Language barriers need to be considered in hosting further workshops to ensure that we capture the voices of all people.

The multi-disciplinary team from Tafta who participated in the forum benefitted from the discussions as it generated a deeper insight into the experiences of care givers and care receivers.

“ The forum highlighted the pressure and stress that caregivers experience, which most people are not aware of.

There is clearly a need for support to caregivers to prevent carer burnout which can lead to serious issues like mental health problems for the carer, elder abuse and so on. The idea of creating a data base of persons living with dementia which will assist SAPs in tracing them when they wander off, is a critical one. It unmasked so many needs and problems our care givers and elders face. Especially the need for training and information/resources for caregivers e.g. a resource centre (knowledge, information, equipment, tips etc.).

One of the most pressing issues arising are the challenges experienced by caregivers and their needs e.g. the emotional toll of ongoing care to older family members. The guilt experienced from taking care of themselves, limited knowledge of caring e.g. understanding Dementia, how to prevent bedsores, how to lift and move a bedbound person.

**Ruyterwacht Senior Centre
Ruyterwacht Older Person's Forum**

I am most grateful and excited that my management team and full management board has bought our senior centre into this programme and sincerely hope and visualise that this is only the beginning of something much greater to be established in Ruyterwacht and surrounding areas.

The feedback received from community members is very positive and the full participation of delegates are of opinion that this project is long outstanding and all are willing to participate to ensure success.

The forum was accepted with open arms and has created a belief that better things are about to realise.

“ One of the main issues we face is the lack of understanding of the greater picture of caregiving and the lack of support - internally and externally.

Support groups within communities would be of assistance in waiting for a permanent resolution for better service.



ECM - Silver Stars

We are humbled that we could in some way be a part of The Family Caregiving Programme. The fora gives more insight to the distress of older persons and now we are able to relook at ways possible to meet the need in the community we serve.

With our community worker having been an integral part of the fora and ongoing work, the experience helps him be more effective and efficient in his role.

“The fora was informative and members of the community appreciated the platform a space to be heard

The forum demonstrated the challenges experienced by older persons and their carers to access basic care and support services needed.

There were several issues presented, especially:

- Lack of support services - limited time or extent of caregivers appointed and seemingly lack of them being accountable or supervised.
- Long waits for medical assistance - call outs for ambulance as well as long waits at the hospitals.
- Limited resources when it is offered by state facilities (adult diapers etc).
- Household income limits dignified care.

Relatives or those caring for older persons are simply doing the best they can with what they have - they don't have the experience but manage through trial and error. There is limited access to support/counselling for them and they continue doing what they have to do at the expense of their own wellbeing which often 'manifests itself' through physical and mental health conditions.





GAPA Khayelitsha Older Person's Forum

Grandmothers Against Poverty and AIDS was delighted to host one of the Older Persons fora with Family Caregiving of Older Persons in South Africa research team on 29 March 2023. As an organisation with 34 seniors groups across Khayelitsha, we tend to be more connected to our older persons who are still mostly independent and active. This forum allowed us to reach out to our seniors who had become increasingly dependant on their fellow group members and family members – it also highlighted seniors who were caregivers of their older siblings within our fold.

This was a helpful exercise as it gave these seniors and their caregivers a platform to share their experiences; what has enabled their care and what they have found challenging. Many attendees were grateful for this forum, especially to have their issues centered in a conversation. They also found comfort in knowing their experiences were shared and not isolated. Lastly, there were knowledgeable practitioners present at the forum who could respond to some of the questions and comments and connect people to resources.

It was an important forum for us as it is a natural progression of ageing that our members would need an increasing amount of care. As an organisation, it is important that we think about how to support our older persons at every stage. Hearing about the difficulties faced by this portion of our members really aided us in thinking through what this support can look like.

“ The most pressing issues were that support services were inaccessible to non-existent

Attendees shared that it is difficult to find home-based carers to lighten the load and also lamented the lack of old age homes within the community; leaving seniors who are being neglected by their families in precarious situations. These paired with general tight budgets and safety concerns leaves older persons feeling vulnerable.



YIZOKUDIBANA NATHI

Iqumrhu/Ibhunga Labantu abadala

'Ikqubo yenkathalelo yosapho'(Family Caregiving Programme) imema bonke abantu abadala,abantu abanika inkathalo kubantu abadala kunye nabo babandakanyekayo ekunikeneni ngeenkonzobazokudibana kulengxoxo!

Indawo: GAPA eholweni (3 Qubaka Cres, Village 2 North, Cape Town, 7784)

Umhla: Ngolwesithathu, 29 March 2023

Ixesha: 10.00-12.00

Iziselo zizoba khona

@fam_caregiving

www.familycaregiving.org.za

KEY FINDINGS

Challenges of Family Caregiving

Family Carers' Need Support

Carers incur high levels of financial, personal and physical strain.

There are few community or health-related resources for family carers. There is little information or training available to family carers who are largely invisible to health care workers and the community. We urge the state to strengthen its capacity to deliver community and home-based care services.

Cost of Care

The rising cost of food, transport, electricity and medical supplies including bed linens or incontinence products, does not support adequate care for older persons. In particular the cost of transport for older persons with high care needs is often unaffordable and leaves many services inaccessible. Whilst the Grant-in-Aid is designed to support the cost of care of older persons who require full time care, few people know about it and even fewer people know how to apply for it. We would call for an investigation to review the amount of the Grant-in-Aid to assess whether it adequately supports elderly care.

Intergenerational Tensions

In contexts of poverty and high unemployment, care for older persons must be understood as being part of family care more broadly.

Whilst many older persons use their Older Person's Grant to provide for adult children and grandchildren's care needs, seeking and obtaining good quality care from younger family members often involved conflict. Older persons are simultaneously care providers and receivers and in the absence of greater employment and state safety nets for young adults, more strain is placed on the older person as financial provider and often carer even when they too need care.

KEY FINDINGS

Community Support Services

Limited Support Services Available

Older persons, family caregivers and home-based carers and community healthcare workers all complained about the lack of support from social workers.

This was seen as a grave challenge as it made accessing formal care services such as residential care impossible. Accessing healthcare support after hours was very challenging with long waiting times for ambulances.

Accessibility of Services

There are many gaps in older persons ability to access services

With transport options limited and costly, many caregivers and older persons were unable to access a service, even if it was available. At times, information on how to access services was unclear. In areas where there is home-based care for older persons, many older persons were unclear how to register for and get support from home-based carers. At the same time, careworkers explained how high caseloads across multiple communities and safety concerns, prevented them from giving more support to older persons.

Ageist Services

There is discrimination directed against older persons in accessing many essential services such as the clinic, hospital, SASSA office etc. There are few visible policies in place in a range of state and private institutions (such as shops and banks) to assist older persons in accessing services.

More is required to assist service sectors in recognising the needs of older persons

Recommendations

The Funding Elder Care Provision in South Africa Report outlined several recommendations including the urgent financial support that is required at community level to attend to and better meet the needs of older persons and their caregivers.

Greater collaboration across state departments and agencies

Many of the findings of the report point to the need to have greater coordination between DSD, DoH, state agencies such as SASSA to provide more effective services to older persons.

Clearer information on geriatric care

One pressing need for caregivers is for more information on specific illnesses. Care givers and older persons were keen to know more about what to expect from certain conditions, especially dementia and Alzheimer's but also stroke recovery and rehabilitation.

Improved Communication and cooperation between healthcare workers and family caregivers

We would recommend better communication between family caregivers and healthcare professionals at service centres, hospitals and clinics, especially in cases where the older persons have high care needs. Occupational therapists and other health professionals could run basic workshops and training for family caregivers and community healthcare workers on geriatric conditions and what to consider when interacting with an older person.

Increase funding to include more health care services

Some of the frustrations expressed by home-based carers and family caregivers in relation to the support they receive in caring for older persons with high care needs, could be assisted with more support from occupational therapists. Here we recommend increased state budget allocation for greater support with aging in place.

Recommendations

Continued...

Increase number of social workers available

The state needs to urgently address the shortage of social workers and develop a strategy to employ and provide specialist training to support the care of older persons, including psychiatric care services.

Transport

We would highly recommend that a 'dial a ride' service and/or mobile clinics for older persons could be offered by certain clinics/hospitals in situations where mobility issues are severe. Current 'dial a ride' services have long waiting lists, whilst ambulance services are not readily available.

Key Service Providers and Public Spaces

There needs to be an awareness at key service sites about the challenges and needs of older persons and their caregivers. There are key sites that older persons attend, such as the clinic, hospital, SASSA office to name just a few. At such sites, porters and security personnel should be trained in supporting older persons and older persons should be given preferential treatment. Whilst this is the policy in some cases, it is not always adhered to.

Grant-in-Aid

More information and clarity are required on the process of supporting older persons who require significant care and may be eligible to obtain a Grant in Aid. Review whether the process for application is older-person friendly and whether the amount is sufficient to adequately support the care needs so they can remain in the family.

Including family caregivers in support programmes

Organisation that run services for older persons need to be better funded to provide greater depth of services, including support groups for family caregivers.

FINDINGS

EXPERIENCES AND CHALLENGES OF FAMILY CAREGIVING

“ Before I leave in the morning, I have to make sure everything is close to her, she also takes insulin so that has to be ready as well. Every morning I prepare her needles, food etc things like that, before I leave to attend my classes because she can't see properly and her knees also give her issues...It's challenging because when I'm not home, I'm always worried about her and I have to come back as soon as possible. I have to accompany her everywhere because she is not able to travel alone or do things independently. It seems like older people are not given any attention, for example we went to the clinic last week and came back around 4pm in the afternoon. We arrived in the morning, there was no consideration that she is an older person. So, I always have to go stand in the line for her in all these places. I can't afford it, I'm not employed. I'm doing a learnership, I get a small stipend...

In hearing the experiences of caregivers and careworkers across the six fora there were three main themes raised: family carers' need for support with caregiving; the cost of care; family and intergenerational tensions.

Family Carers' Need for Support

Family carers' need for support dominated discussions in both the Western Cape and KwaZulu Natal. A consistent theme across all fora in relation to caring for an older person was the physical and emotional toll carried by family caregivers. Family carers expressed a deep need for support from a range of service providers. Family carers spoke about being unsure what the illness and expectations of a particular illness may mean for caregiving responsibilities. One participant stated:

“ There is no training for a family carer. What is a bedsore and how do you prevent it? How do we lift and move a bed-bound person? ”

Moreover, family caregivers wanted a better understanding of the medication prescribed, especially as older persons were at times averse to adhering to the medication. As well as feeling unsure, they feel their work and role is being undermined as there were few consultations with nurses, doctors, healthcare professionals and no training in the community on specific conditions and potential warning signs.

Family caregivers were particularly aggrieved and frustrated by their invisibility. Whilst a family caregiver is constantly observing and recording what is happening in caring for an older person, the lack of engagement with medical and health professionals, either at hospitals or in the community undermines their authority, knowledge, and insight. Yet medical and health careworkers and family caregivers have a shared interest in doing what is best for the older person.

Another important feature shaping the experience of family caregivers today is the lack of support for caregivers. One participant in Durban stated:

“ Caregivers need to be strong and I need a space to cry, talk and vent. ”

Deeply ambivalent feelings of guilt for wanting to take care of themselves, wanting to sleep, having days off, sat alongside the pressures of being the sole caregiver or needing to put the interests of the older person first. As such the personal and familial effect of daily care, and in some instances cumulative care, caring for one older person and then another, was expressed in the fora.

Many caregivers, especially caregivers supporting older persons who have high care needs, described the non-stop work required of older persons who are bed bound.

Caregivers expressed concerns about their own wellbeing about the lack of sleep or having physical pain. Many of the caregivers are older persons and may be living with arthritis, hypertension, diabetes, or other conditions. The physical requirements of being a caregiver, especially to older, larger men, who needed to be washed and turned in bed were very demanding and at times impossible. One caregiver in the Western Cape, who received a disability grant herself for her arthritis condition, expressed feeling uncomfortable caring for an older person not only because he is male but also because he is three times her weight. She stated that “if the home-based carer doesn’t come, the older person does not get washed”, because she can no longer do it. She also expressed having difficulty with taking the older person to the clinic or hospital, mentioning that at times she would have to get there first so that he does not have to wait too long in a queue. Whilst putting him first, this did mean that she had to leave the house at 05-30 and sometimes only gets back after 16.00.

Care receivers shared their experience of receiving care and expressed the value and additional benefits that came with formal support. In one forum in KwaZulu Natal, older persons spoke about the dislike of being dependent and the constant feeling of loss. The loss of the capacity of doing everyday tasks and the difficulties that come with requiring care support.

***“Muthande Society for the Aged Home-Based Care Services, the biggest community based home care services in the eThekweni Municipality, lost 63 Home Based Care workers during Covid-19 due to lack of funding. This was and still is a major loss to the poorly looked after African senior citizens in South Africa.*”**



Cost of Care

“ I have an older sister; she is the first born and I’m the 6th after her. She is not well, she is old. Every week I must go to the clinic for her medical needs...It’s really hard because an older person like her has the same needs as a child. I have to bathe her and all those types of things. I’m also old, but I must take care of her. I wake up in the morning to cook things like porridge for her. I cannot take her to an old age/care home because people will say I have abandoned her. we are the only surviving siblings, only the 2 of us are left[alive] now. all our other siblings have passed on. My pain comes from that situation. Even the money we get is extremely limited. The money she gets is all spent on her care needs because like a child, I have to buy nappies, food, clinic visits, bathing.

The cost of care was another dominant theme identified in relation to the challenges of family care, something that featured in all fora. The cost of transport, food and electricity, amongst other things means that family caregivers and the families still have to sustain their livelihoods whilst incurring additional costs that come with caring for an older person. In some instances, the cost of transport to assist people who are bed-bound or have conditions such as emphysema and need specialist transport, was very high. These are costs that can’t be avoided and so participants in the fora explained the different strategies of how they manage. For instance, one participant explained how she had to walk around, knocking on doors, asking others for money to help with such cost. In one community, the participants at the fora discussed how government-supported transport services (Dial a Ride) was heavily oversubscribed. In most fora participants stated that ambulances were not available which often led the older persons unable to access treatment.

The cost of consumables, especially adult incontinence products, was also a source of hardship for many families. Adult incontinence products are approximately R220 for 10 and for older persons who require almost constant use, this is a huge expense. In many of the areas, adult incontinence products were supplied by the clinic or via the home-based carers, but this was irregular (with sometimes supply delays for up to 3-4 months) and not enough. One participant, a caregiver stated: “buying nappies and everything for her, sometimes we run out before social grant dates.”

Many of the participants felt that the rising cost of living, especially food, was unfair on older persons, and securing healthy food was becoming more difficult, in a context of high unemployment in the country. In a context when over 70 percent of the older person population receives a grant, one person stated: “pensioners are being priced and charged like everyone else in the supermarket, knowing very well they only dependent on the grant.” Some family caregivers explained that they ended up taking loans to cover the extra costs which was adding to the overall cost of care. As we will discuss later in the report, many participants in the fora were unaware of the Grant-in Aid, which could assist with some of the high costs. For people who knew about the Grant-in-Aid, there was much confusion about how to access it and the eligibility requirements.



Family Dynamics and Intergenerational Tensions

“...the things we see as older persons need to be addressed. You have heard our cry. Our children are not working. Now we don't even have healthcare workers, but we have children who have passed grade 12 but they are sitting at home. I wish there was a plan or some training for them to find employment/ have income. If they work, they would be able to help so that will lessen the burden on older persons. The load of having to take care of everyone in the house from great grandchildren to grandchildren to their own adult children who have nothing to do at home.

One of the main themes that arose in the fora was the intergenerational tensions experienced by both family caregivers and older persons. For some participants attending the fora, the younger generation were perceived as not supporting the care needs of the older person or the caregiver and were perceived to be out of control. This manifested itself in different ways; in some instances, the younger generation were not reciprocating care, not visiting enough and not helping; in other cases, the younger generation were seen to be abusive. Issues around drug and alcohol misuse arose frequently in the fora and these issues were discussed in ways that led caregivers and older persons to feel a lack of control over their (adult) children household members. One woman gave the example of calling the police regularly as a way of removing the tension from the home and seeking external help.

In the context of high levels of unemployment, older persons and the caregivers were supporting adult children both financially and practically.



In such ways, older persons, mainly through the Older Persons Grant, were being called upon for financial assistance. In this way it was perceived that the presence of an older person in the house was crucial to sustaining the livelihood of all family members. Some participants felt that older persons were being financially abused in ways that the OPG was misused and only the bare minimum food supplies and needs of the older person would be met. One older person in a forum in KZN spoke out and explained that there is a lot of stress and pressure living with grandchildren who are unemployed, as they are stressed and vent out their anger.

Home-based carers had quite a lot to say in this regard and spoke about these issues in relation to the provision of food for the purposes of medication adherence. One home-based carer stated,

“There are households where the only income is the older persons income and there is food lacking in the household and the older person needs food to take ill/medication.”

Other issues raised by the careworkers in relation to intergenerational conflict related to the care and dignity of the older persons when adult children are perceived to be negligent. One care worker mentioned that “some of the older persons wet themselves and are not cleaned at times until the care worker comes to change their adult diapers.”

Across all fora there was agreement that family caregiving of older persons, whilst rewarding, is very challenging. The challenges encountered within the household was coupled with challenges in accessing services at the community level, which we will outline in the next part. Whilst participants identified the challenges in the everyday experience of family care both at a household and community level, they also had suggestions for how some of these could be addressed. In part three we document the ways in which services and support for family caregivers could be improved.



SUPPORT SERVICES

“

There is no help. Help is only available at some NPOs. They have their clubs and people who are close are able to use the clinic. I can confirm that. But some clubs are far, I wish there was help closer to our areas because the NPO cannot help all the sections. Some sections can get some services as well instead of just having help at one section only. I wish there was more help like the one offered by this NPO, things like the clinic and clubs.

Services for older people living in the community are critical to supporting family care. There were three main themes in relation to the problems in accessing support services for older persons: accessibility issues of existing services; support services not available; and services not adapted to cater for older persons.



Accessibility of existing services

Across all fora, older persons and their caregivers spoke about how accessing medication can be challenging as clinics can be far or transport costs to get to the clinic are high. Whilst in some areas home-based carers provide medication, other people in the other fora complained about poor quality services from healthcare workers. Older people who are on chronic medication are required to visit the doctor every three months, but this is extremely challenging for people who have mobility issues. Family caregivers incurred great expense and challenges in getting older persons who have high care needs to such appointments.

Moreover, issues around post-discharge care from hospitals was raised as a serious concern. Caregivers in both provinces voiced a need for support in obtaining and learning how to use equipment for a bath, shower, and a commode. They expressed the need to learn about and understand the condition and to learn how to care for an older person who is bed-bound and how to lift them and move them. Accessing wheelchairs was difficult at times and in some cases older persons and their caregivers waited up to two years to get broken wheelchairs fixed.

“The government must please try to help us in our households. If the healthcare workers were deployed, they would see that this is true. Some [older persons] leave home without even bathing, they rush to the club so that they get a plate [of food]. We really have a problem as older people. When I visit some older people [in their houses], they complain that their feet hurt and are swollen and that is the reason “I couldn’t come to the club.” Such things can be helped by healthcare workers but there are no healthcare workers available/deployed.

Accessing home care was challenging and in some fora this opportunity was not even possible. In areas where it exists, family carers explained that the process for obtaining home care was unclear. It was unclear whether you must register at the hospital or if the hospital must refer you. Information on how to access these services and what they entail need to be clearer and well communicated.

In addition to accessing home care services, there were concerns raised across many fora regarding the quality of home care services. One participant in the Western Cape stated, “poor quality home care is provided by demotivated, poorly paid people who don’t clean, eat people’s food and are not held accountable, and it is not clear how quality assurance processes work.” In the areas that had home-based care services, there was an acknowledgement that such services did support family care. However, careworkers, in sharing their experience of supporting family care, expressed many frustrations with working alongside families in the community. It was felt that families in the community misunderstand what home-based carers are being paid to do and what support they can offer. One home-based carer in the Western Cape stated that when there are older persons that tell her she needs to check their blood pressure, she does not like how that makes her look to others, as if she is a bad care worker. She understands the families’ frustrations, but she feels that is unfair on home-based carers. Home-based carers are often employed by Social Employment funds or EPWP and often hold temporary contracts which is often very poorly paid.

Moreover, she tried to explain that they have extremely high caseloads as their responsibilities are not focussed on older persons but also include people in the community living with TB, HIV and neo-natal care. Whilst they support older persons with washing, wound dressing, catheters, they have a larger scope of patients too and are not dedicated care service for older persons. In supporting older persons, home-based care workers often work overtime and after hours and contest their contractual obligation as understood by their employer as they see the need to support some families.

In our work in some areas, we could see that there were large gaps in terms of service provision by government and NPOs. Community care workers had very large roles and responsibilities and were stretched in terms of capacity and scope of role. In the areas where they did operate, they were undertaking essential care activities such as washing, providing respite care (if only for a limited time) and often stepping in around cases of neglect.

In our recent report on funding elder care provision, we highlighted how funding for community and family-based care has decreased by 13% over the last 18 years. Here we see how the limited funding for community support and interventions of careworkers or occupational therapists impacts the type of care that can be provided.

“ Why are social workers so scarce/limited? We don’t see social workers in our areas and why is it that when our children want to quit drugs, there are no services available to help? I’m talking from experience because I have a child who has been expressing that he wants to stop smoking [drugs] but I have been everywhere, I’m not getting any help [for him]. How come we don’t have social workers who can help with such issues or where can we go for help?...”

One of the main grievances across the two provinces, expressed by family caregivers, older persons and careworkers is that there were not enough social workers. The lack of social worker capacity and perceived interest made accessing formal care services such as residential care and/or reporting/investigating elder abuse very difficult. Home-based carers also raised this as a critical gap in supporting care of older persons and caregivers. Some of the careworkers explained how they reported cases to social workers and the police, where they were concerned about the care of the older persons, but nothing ever happens. In meeting with various stakeholders, including Age in Action in the Western Cape, we learned that whilst social workers do assist with the reporting of elderly abuse cases, the costs of getting social workers to communities is becoming more difficult.

The third main concern related to support services is that they do not cater for older persons. Issues about services being ‘ageist’ dominated the discussion across all fora. Whilst it came up in relation to most state services, it was particularly relevant in relation to accessing services at the South African Social Services Agency (SASSA). For older persons and their caregivers who access their state grants at a Shoprite, almost all participants explained how paydays are extremely challenging, with long distances to a Shoprite followed by long queues. More importantly, queuing at SASSA for older persons is very challenging as grant applications and renewals require letters and older persons are often required to line up and stand in queues for long periods, both in winter and summer. In this regard, all participants discussed how more attention needs to be given to older persons in public spaces, such as clinics and SASSA offices but also in banks and shops, so that persons with significant care needs, not only those in a wheelchair, can be prioritised. In some settings, such as clinics, they might be the official policy but members of the fora reported that it was infrequently adhered to.

There was also a consensus within most fora about the safety concerns with queueing at SASSA offices as some of the areas are dangerous and people are robbed waiting there.

Many participants in the fora were aware of the Grant-in-Aid but the process for applying for and obtaining it, including the process of obtaining medical assessments were unclear. Moreover, the criteria used to apply for and obtain a medical assessment seemed to get in the way of accessing the grant for older persons who has high care needs. Greater clarity is required in this regard, given the essential support a Grant-in-Aid can provide.

Participants also identified some challenges in the community in relation to general services, such as SAPS and transport services, that also need to consider the needs of older persons. In many fora, caregivers and older persons felt it was important to educate the police and community members about the specific access issues that older persons with high care needs may face but also to educate the police about what certain conditions such as Alzheimer's and Dementia might mean when engaging in community or family matters.



Older Persons Forum

The Family Caregiving Programme invites all older persons, caregivers of older persons and related professional service providers to the Eerste River Older Persons Forum

PLACE: 19 Bahia Crescent, Malibu Village, Bluedowns, Eersteriver (The entrance is on London Way)

DATE: Monday, 13 March 2023

TIME: 17:00-18:30

REFRESHMENTS WILL BE PROVIDED

INFO@FAMILYCAREGIVING.ORG.ZA
WWW.FAMILYCAREGIVING.ORG.ZA

SUPPORT SERVICES

“ ...the government must try to care for us because we are now trying to care for ourselves, through doing these groups. They should check on us in the groups, we don't have stable places to meet. We go around looking for vacant spaces, put together money and rent out a particular room. If we had our own place, funders, organisations, healthcare workers would know where to find us as older people. Yes, there are rooms, but they are far...we don't have a place to host the groups. We don't have a space to cook our soups.

In this chapter we map out ideas and possibilities for the future. These ideas have their origins in older persons and caregivers' experiences and suggestions. Whilst we recognise that some of these ideas may be relatively easy to initiate, we realise that some may carry significant costs.



We want to remind the state that the cost of some of these ideas and initiatives is always less compared to the costs of dealing with the issues they are trying to prevent. Across the fora, we worked in communities that have access to different resources. In communities where there are active service centres, they are perceived to offer a wide range of essential support for care receivers. In some instances, there are also services for family caregivers, but this is not as common. We want to commend the critical role and support that such services offer. In many instances volunteer groups, religious and community organisations also provided food programmes or soup kitchens or other supports for families (not specifically older persons) and this was also believed to be an essential service.

In supporting older persons and the care of older persons, the suggestions and requests below are to be understood as cutting across departments, sectors and state and community organisations. Rather than thinking about older persons support services as being the domain of DSD, we understand that services that support older persons should involve several departments, especially health and build on the local and community initiatives and programmes that exist.

The first key recommendation is a request for clearer information. Information on care for older persons and their needs is essential for not only caregivers and care receivers but also wider community members. There are many myths circulating in relation to specific illnesses and campaigns to dispel such myths would assist family caregivers and older persons in negotiating the everyday. In this regard, we would suggest that greater understanding of some illnesses that impact older persons becomes an important features of training members of the police force and religious leaders.

Moreover, information packages for specific conditions are essential. Care givers and older persons were keen to know more about what to expect from certain conditions, especially dementia and Alzheimer's but also stroke recovery and rehabilitation. The experience of being discharged from hospital and starting the care practice is a key moment in supporting families. Family counselling and dialogue during the transition to care is required. We would also advocate for home visits and check ins with the family for a period of at least 6-8 weeks following discharge. Family mediation or counselling offered through organizations such as Families South Africa (FAMSA) is critical for assisting caregivers and receivers who transition into requiring high care. The opportunity of different family members to discuss particularities of the change in circumstances is essential for ensuring good quality care.

We would also recommend some training for family caregivers who are responsible for caring for older people who are bed-bound or have other specific requirements. Supporting family caregivers with skills and knowledge about the condition will improve the quality of care received. We recognize the work that Alzheimer's SA and Dementia SA undertake through support groups but often the reach is limited and quite specific.

There are many concerns and challenges with transport, both in terms of its availability, safety, and cost. We would highly recommend that a 'dial a ride' service for older persons could be offered by certain clinics/hospitals in situations where mobility issues are severe. Mobile clinics are very much needed to help those who are struggling to walk. Some older persons are relying on Uber as a more bespoke door-to-door facility when affordable. Our suggestion is to develop the capacity of older persons and family caregivers to draw on such e-hailing services and support the cost through a range of methods.

There needs to be an awareness at key services about the challenges and needs of older persons and their caregivers. There are key sites that older persons attend, such as the clinic, hospital, SASSA office to name just a few. At such sites, porters and security personnel should be trained in supporting older persons and older persons should be given preferential treatment.

More information and clarity are required on the process of supporting older persons who require significant care and may be eligible to obtain a Grant in Aid. The findings show that the process is unclear, there are some misconceptions about this, and the low uptake is perhaps revealing the difficulties in accessing this grant. Providing support for caregivers is essential.

In some senior service centres, programmes are run for caregivers. However, this is limited. At the community level, networking amongst families and caregivers who are experiencing a similar challenge or situation could be developed. This is one of the outcomes of our work which has created a great deal of support for caregivers in two communities. Caregivers need a resource centre (knowledge, information, equipment, tips etc). Organisations that run services for older persons need to be better funded to provide greater depth of services.

Caregivers also need better interaction with community care workers and health care workers. Caregivers in this instance can be proactive by diarising the care receiver's daily challenges and assessments can be conducted that can provide healthcare workers with an overview. Moreover, training for healthcare workers on geriatric conditions and what to consider when interacting with an older person is essential.

At the community level, it is possible for street committees to play a more active role in assisting caregivers and households. Together with key service providers, creating community networks for emergencies but also for assistance with physically lifting older persons, where required, is an essential way in which communities energies and input can be harnessed.

Prepared for The Family Caregiving of Older Persons in Southern Africa Programme

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Thank you to all the participants and partner organisations