[RESEARCH ARTICLE]

Care workers' perceptions of the programme for learners with severe to profound intellectual disabilities in Nkangala District Mpumalanga: "*Nothing about us without us*"

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ABSTRACT

Background: The South African Department of Basic Education (DBE) has recently implemented a learning programme for learners with severe to profound intellectual disabilities (LSPID) in the stimulation care centres. Outreach education teams, including multidisciplinary rehabilitation professionals and education specialists, provide LSPID learning programme training to capacitate and equip care workers in stimulation care centres (SCCs) to afford the previously marginalized children an opportunity to receive quality funded education and rehabilitation.

A staff audit of SCCs in the Western Cape revealed that 40% of care workers were parents of children enrolled in the centres. However, these care workers, along with others, lacked formal training in early childhood development, health, and rehabilitation essential for providing educational support to learners with severe to profound intellectual disabilities (SPID), a condition prevalent in the Nkangala district of Mpumalanga Province. In response, curriculum specialists and therapists developed a learning programme to train care workers across the country. However, little is known about the experiences and expectations of the care workers, as there has been limited research in this context. For instance, it remains unclear whether the training introduced in 2018 adequately met their needs. To address this gap, it would be beneficial for the DBE to collaborate with care workers by exploring their experiences and creating a platform for their input in policy formulation. Furthermore, care workers were excluded from executive planning, which impacts the outcomes of the LSPID programme, even though they are key role players whose support is crucial for implementing DBE strategies and activities. Consequently, care workers may be hesitant to fully engage with the learning programme and training if they feel they have not had an active role in shaping decisions and outcomes.

Aim of study: To explore the perceptions of care workers in special care centres supported by the Department of Social Development in Mpumalanga Province, South Africa about the learning meme and the training provided by the outreach education team.

Methodology: A descriptive explorative qualitative study was used to explore the perceptions of 12 care workers who were purposively selected. Data collected using semi-structured key informant interviews were thematically analysed, using inductive coding.

Findings: The care workers appreciated the learning programme, which they believe capacitated them to provide comprehensive intervention, stimulation, and formal education to the children in their care. This programme also contributed to better-resourced working environments. Despite their positive lived experiences of the changes facilitated by the LSPID learning programme to services provided over the years, the care workers felt side-lined and undermined. The Department of Basic Education did not seek their collaboration in major decision-making and the training they received was not accredited.

Additionally, the care workers did not receive recognition in terms of remuneration for the extra set of responsibilities and duties that came with the implementation of the LSPID learning programme.

Conclusion: The LSPID learning programme is experienced as partially solving the problems that it was intended to address. The care workers expressed a desire to receive formal accredited training towards a qualification in providing care and education to learners with SPID and be remunerated for implementing the programme.

Implications for practice

- The contributions of the outreach education team can potentially improve outcomes of the programme and give the care workers tools to confidently address challenges encountered in providing the LSPID learning programme.
- The care workers' views have the potential to inform Department of Basic Education (DBE) policy to cater for their needs and those of the learners with SPID in the SCC's.

INTRODUCTION AND LITERATURE REVIEW

There is no justice when others are intentionally ignored[1,2]. Care workers in stimulation care centre (SCC's) for children with severe to profound intellectual disabilities expressed that their voices are often unheard, and their input is not sought for on important issues concerning the operations at the centres. There are significant gaps in the engagement, involvement, and collaboration of care workers in contributing their insights and perspectives on issues related to the operations of SCC's and the education of children with severe to profound intellectual disabilities (SPID). These gaps arise from a lack of formal mechanisms to include care workers in decision-making processes, resulting in policies and practices that do not adequately cater the practical challenges and needs observed by those doing the groundwork[3].

Service provision and livelihood improvement for children with disabilities is an ongoing process in developing South Africa. Despite disability legislation supporting the inclusion of children with disabilities, including those with SPID and integrating them into broader society and services in South Africa remains a challenge. This difficulty is compounded by the perception that the children with SPID are a societal impediment and that their needs are seldom met[4].

Intellectual disabilities are described according to the individual's level of cognitive and adaptive functioning across conceptual, social and communication domains. This includes their performance of everyday activities on a developmental continuum, quantified by performance on intellectual ability assessments[4]. Although the prevalence of intellectual disability in South Africa has been indicated as higher than in high-income countries[5], no recent accurate South African statistics are available on the prevalence of SPID. An estimation of 1% of severe difficulties in cognitive abilities has been reported[5]. For the reason that throughout their lifespan, people with SPID will be dependent in activities of daily life[6], parents should adjust educational expectations to the achievement of basic skills, independence in activities and community integration[7]. Children with severe intellectual disabilities (IQ 20–34) or profound intellectual disabilities (IQ 19 or below) require extensive assistance and supervision from care workers. The care workers, who may include mothers or unemployed community members seeking work in SCCs, provide the necessary support as these children are unable to care for themselves independently[4]. Prior to 2010, few educational services for learners with SPID existed in South Africa and they were excluded from education as they were considered to be uneducable[8]. The Department of Basic Education (DBE) in South Africa did not cater for learners with SPID even though the Constitution of South Africa[9] and the Bill of Human Rights[10], emphasized the right to education for all children irrespective of disability[11]. The services that existed for children with SPID were often under-resourced and provided by untrained care workers[12]. An audit of staff in the Western Cape in 2016 in SCCs where these children were cared for, found that 40% of care workers were parents with a child in the centre[12]. These care workers faced a high burden of care due to the leaners with SPID's impaired sensory, intellectual, and communication abilities as well as the increased likelihood of epilepsy and motor dysfunction. This high burden of care, posed a risk for burnout which resulted in a high turnover of staff at SCCs[13]. Many of the care workers and other staff working in SCCs in South Africa[14] were found to have had no formal training in early childhood development or health and rehabilitation required to provide educational support to the learners with SPID[12,15]. This increased the stress of caregiving which was exacerbated by the low wages typical of this work. As a result, the care workers' physical and mental health were negatively impacted[16].

In 2007, the Western Cape Forum for Intellectual Disability achieved a court ruling compelling the Western Cape Education Department (WCED) to provide access to affordable education for learners with SPID[17]. Following the court ruling, these care facilities were expected to offer a daily programme that is intended to provide not only care but also stimulation using a LSPID learning programme. A Department of Basic Education LSPID learning programme curriculum was developed by specialists and therapists for care workers to implement in the SCCs[18]. This programme was based on the Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability[19], which indicates that the learners with SPID benefit when their education is aimed at developing communication, personal and self-care, as well as practical and conceptual skills rather than in academic skills. While it is accepted that learners with SPID can learn and develop with appropriate input, they also require full-time care as they have physical and cognitive limitations. They are thus dependent and/or require assistance in activities of daily living[19].

In 2016, as the project made progress in the Western Cape, the court order was expanded to mandate services be provided by all Basic Education Departments in all nine South African provinces[19].The project was officially piloted in 2017 countrywide and introduced to the Mpumalanga care centres in 2018. An educational outreach team comprised of occupational therapists, physiotherapists, speech therapists, education psychologists and senior education specialists were employed and mandated by the DBE to provide rehabilitation, education and most importantly to train the care workers to execute the LSPID learning programme[6].

By nature of the care worker's daily job and responsibilities, they spend considerable time with the children. Therefore, the care workers were to be the main executors of the LSPID learning programme rather than the education outreach team, whose role was to provide training, scheduled visits and support[6]. The care workers employed in the SCCs, provide physical care of learners with SPID, including changing nappies, feeding, administering medication, facilitating mobility, and monitoring postural and positioning requirements. The implementation of the LSPID learning programme subsequently required care workers to assume an educational role and create an enabling environment for promoting communication, skills training and independence so that the learners with SPID develop to their full potential[19]. To address the gap in research and to honour the inclusion of the voices of the care workers, this study engaged with the care workers in Mpumalanga Province to explore their perceptions about the LSPID learning programme.

METHODOLOGY

Against the backdrop of the research question of the study, the objectives were to explore: a) the lived experiences of the care workers in providing services for children with SPID in their communities; b) the perceptions of the care workers of the learning programme for LSPID; and c) perceptions of care workers after six to twelve months about the effectiveness of the learning programme for LSPID and the training on the programme received from the education outreach team.

Study Design

A descriptive, exploratory qualitative research design was used because it was ideal for systematically gathering information in a situation where no previous data were available[20]. This approach allowed for a detailed exploration of care workers' perspectives, providing rich data through in-depth interviews.

The research context from which the participants were recruited involves the SCCs which are located in the rural district of Mpumalanga Province, where challenges with basic resources like water and sanitation are common[21]. At the time of the study, a total of 10 SCCs, 107 care workers and 476 learners were serviced by the education outreach team in this district. Four out of the 10 SCCs are well-resourced and supported by foreign missionaries while others consist of informal structures or shacks. Both the care workers and learners with SPID come from low socio-economic settings. The centres receive financial support from the centre care fees, Department of Social Development(DSD) and sometimes private sponsors.

The researcher used purposive sampling to recruit 12 participants who met the eligibility criteria. These criteria included being a care worker in the SCCs in Mpumalanga who had received both centralised cluster and onsite training from the education outreach team on the LSPID learning programme and had interacted with the team for a period of at least six months.

Research instruments

In terms of the research procedure, a short demographic questionnaire was administered to gather information on personal details, place of residence relative to the centre, education level, and care workers' experience with LSPID. The researcher used an interview schedule for semi-structured, one-on-one interviews to explore care workers' expectations and experiences with the training they received, its impact, their feelings about the project, the effectiveness and challenges of implementation, and areas they felt needed improvement. Semi-structured interviews were chosen for their flexibility, allowing for deeper insights by accommodating strong emotions or expressions while still adhering to a set of predetermined questions.

The interview schedule was piloted with a care worker from a different district, and the data from this pilot were not included in the final analysis.

Ethical clearance was obtained from the Human Research Ethics Committee at the University of Witwatersrand (M200983) and permission to conduct research was granted by the Mpumalanga Department of Education and the Department of Social Development. Selected responses were translated by the first author into English and back into Sepedi, a common translation checking method, and reviewed by a co-supervisor who is fluent in Sepedi[22].

Regarding the data analysis, the first author used five steps suggested by Creswell[23] to organise and prepare the data for analysis, review the data, code the data, generate themes, categories and subcategories and provide a description of these. MAXQDA software[24] was employed in the in vivo coding of the 12 interview transcriptions. Rigour of the research was ensured by adhering to the principles of credibility using member checking with the participants to clarify their intentions. The researcher practiced reflexivity to minimise bias through active self-awareness and reflection on her insider role[25]. Dependability was ensured by an using audit trail with critical review of coding[26].

FINDINGS

Demographics

Of the 12 participants, only one care worker was a male and four of the care workers who were the founders of the SCCs were mothers with a disabled child at the centre. The oldest participant was 55 years old and 8 of them were in their 30's and 40's. Only three have been trained in early childhood development (ECD), and two have been trained in home-based care with one care worker formally trained in computer literacy. Half of the care workers in this sample have been working in the SCCs for 5 to 10 years as depicted in Table I (page 3).

Table I: Participant Demographics

Participant	Gender	Age	Highest level of education	Tenure as a careworker (years)
1	Male	50	Grade 12 Early Childhood Development (ECD) Course	12
2	Female	31	Grade 12 ECD Course	6
3	Female	33	Grade 12 ECD Course	5
4	Female	35	Grade 12	3
5	Female	38	Grade 12 Security Guard Training	5
6	Female	43	Grade 12 Home based care	10
7	Female	45	Grade 12 Home based care	8
8	Female	49	Grade 12	7
9	Female	53	Grade 12	15
10	Female	53	Grade 9	17
11	Female	55	Below Grade 9	20
12	Female	30	Grade 12 plus computer literacy	6

Two themes, with their categories and subcategories were generated from the data.

THEME 1. Mollo wo o sa o orego o ka se go ntšhe dipale - "If you do not face the fire you will never know its' heat".

This theme means that the situation is better understood by the ones who "are in it" than by onlookers and describes the care workers' expectations and experiences of the LSPID learning programme and challenges faced; subcategories and categories indicated in Table II (below).

Table II: Theme 1

Theme	Category	Subcategory	Code
Mollo wo sa ooregoo ka sego ntšhe dipale. If you do not face the fire, you will never know it's heat	1.1 High expectations on care workers	1.1 "Old tasks" revisited	Care routine
			Transportation
			Administration
			Clinic/hospital
		1.1.2 "New task" added	Stimulation and teaching
			No added remuneration
	1.2. Perceived low value of our work	2.1 Malalignment of perceived needs and actual needs	Resources
			Skill development
		2.2 Poor recognition of pre-existing knowledge	Left out of decision making
			Years of experience
		2.3 Job (in)security	Will be replaced

The two broad categories that were generated are the high expectations that the care workers must meet as well as the *perceived low value* the learning programme appeared to place on the services they offer.

Category 1.1:High expectations on care workers

In describing the high expectations placed on care workers(Category 1), a comprehensive overview was provided, detailing a typical day for a care worker. This included the duties of the care workers in terms of what they have always been doing (**old tasks; subcategory 1.1**) and the newly introduced job descriptions (**newly added tasks; subcategory 1.2**) that is suggestive of new expectations placed on the care workers. The old tasks include the duties that the care workers carried out prior to the introduction of the learning programme for LSPID and continue to execute. These old tasks incorporate care routine, transport chaperoning, administration and taking the children to the hospital or clinic for their medical review and collection of medication. The care workers explained that they do not only provide care to the children, but they also get up early to accompany them when they are transported to and from the SCC.

"Our caregivers actually start by collecting the children to help the driver, so that they can chaperone the children should anything like seizure attack occur, then the caregiver can be there to handle or assist" **(P7).**

To successfully run their service, they also need to complete administrative duties and report to both parents and government departments.

"We compile the files and make sure that everything that they need is in the files, then we have time to fix our own paperwork so that if the therapists and parents come then they find that we have our documents in place" **(P12).**

The LSPID learning programme, as required by the DBE, mandates that care workers now teach and manage the programme. Given the children's high needs, care workers must integrate intervention strategies into their existing schedules.

"You came, you came with duties for us, you are giving us duties, actually you are adding on top of what we were doing, and you say to us now this is how you are to carry out your duties" **(P5)**

The care workers expressed dismay over the new tasks added to their job descriptions, as these additional duties did not enhance their professional status, nor were they compensated with increased pay for the changes in their roles.

The care workers thus experienced the expectations of the LSPID learning programme as extra work, and it appeared to them that the time required for their old tasks (mainly care routine) are not taken into consideration. The care workers perceive the expectations of the LSPID learning programme as additional work. They feel that the time needed for their existing tasks, primarily centred around care routines, is not adequately considered when they are expected to undertake new tasks. These new responsibilities involve teaching and stimulation activities required to implement the learning programme, which encompasses intensive structured teaching and methods for evaluating the child's progress. This adds to their workload without consideration of their existing duties.

"Now they are coming in with things that I'm supposed to do but they don't pay me to do it, and if you actually look at it, it's like ohk, ohk wait, they giving me a job to do and me doing that particular job they need results at the end of the day, but now they are not paying me to do that, because Department of Social Development (DSD) take for example I'm just making an example by DSD, DSD pays me to change nappies and give food, like that's all, now LSPID comes along, LSPID wants me to complete files, teach children about Covid 19, expects me to be drawing the whole map from the clouds and everything like that and then (shows empty hands), how fair is that?" **(P12)**

Category 1.2: Perceived low value of our work

The lack of remuneration for their additional services led the care workers to feel undervalued and invisible, perceiving that the government departments placed little importance on their work. This sentiment was reinforced by the malalignment between **their perceived needs and the actual needs** of learners with SPID and the SCCs. The care workers also felt that their contributions were overlooked and unrecognised, and they experienced frustration with the DBE resource assistance, which they viewed as arbitrarily chosen without their input, often failing to meet their actual needs

"Those structures firstly need to change, they need to be built. They need to be renovated and changed, to fit those children, uhm ok fine you bring us a TV, but I'm in a shack right now, what if they just open this thing, take the TV what's the point?" **(P12)**

The care workers also felt like they do not get sufficient time for skill acquisition and feedback due to the long turnaround time of the education outreach team visits.

"So, if you come 2 months after having trained me on something, I will carry on with it, but at some point, I will pause and wonder am I still doing the right thing, you see?" **(P5)**

"Ahh, they visit us only once. At least if they could visit us after (every)two weeks, (or) maybe twice per month you see. In the course of implementation, ahh then they are gone, they will only come the following month, you see, at least if they could visit twice or so, to show us here and there, then where we do not understand we can ask for clarity and say here what do we do, you see" **(P2).**

The perception of the care workers was that there was **poor recognition of pre-existing knowledge**. They felt like they do not belong anywhere, they were not seen as team players or stakeholders hence they are left out on matters that are central to their job. They expressed that even if they make inputs, they are ignored as the other stakeholders are better qualified than them (people at the high table, the government, somebody who went to school for 12 years or more).

"Being a caregiver with no platform or with no right to say anything anywhere is actually discouraging" (P12).

We actually don't exist; we don't belong anywhere **(P11)**

They had feelings that their learning was disregarded because it had occurred on the job through experience and years of working with the children.

*"I have been in this field for a long time, and I have so much experience, eh of dealing of ka di situation tša bana ba (**with the situations of these children**) and to get somebody else to tell you about something that you know, sometimes it's a bit boring because you actually know that and some of the things you learn them on your own, to make it easier for your situation to be able to cope, with the children or with a child"* **(P11).**

The care workers expressed frustrations over their work not being valued, being taken for granted and this highlighted the care workers' negative experience of the programme and what they perceived as a threat to their job owing to their level of education and lack of recognition of the extra work they are expected to do. Some care workers fear that the call for providing formal accessible funded education in the SCCs may lead to them losing their jobs if the DBE requires professionally trained teachers and therapists to work with the learners with SPID.

"But because now, government has to take over or because now things have to be done in a professional

manner, you being passionate is not gonna save you, they gonna want somebody who is actually going to provide papers that I went to school and did this, and I'm qualified to do this, so most of us caregivers who are unqualified actually are at risk" **(P12)**

The care workers are of the notion that they **may be replaced by professionals** as they are not valued.

"*The same parents that took the Department of Education to court will be the ones that get us out of our job, saying they want their children to be taught by professionals.How can you teach my child the basics if you yourself are not learned?*" **(P12)**

The care workers stressed that they require accredited training as an indication that their work is being valued and taken 'seriously.' These ideas come from the type of training they get which is not accredited.

"*Do not give us papers that are decorated as certificates, yet they are not accredited*" **(P5)**

THEME 2: Go ba komana madula a bapile - "To be prepared for anything"

This theme, with two ensuing categories and three subcategories depicted in Table III (below), reflect the sense of preparedness gained through training, coaching, and skill-building, which enables care workers to be accountable for their actions, make informed predictions and expectations, assess outcomes, and most importantly, evaluate themselves to improve and grow from their experiences:

Table III. Theme 2

Theme	Category	Subcategory	Codes
Go ba Komana Madula a bapile Be prepared for anything	2.1 Noticeable changes	2.1.1 Care worker capacitation	Improved knowledge
			Practice changes
			Caregiver well-being
		2.1.2 Learning programme - service users and community	Benefits
			Status of centre
	2.2 Care workers input	2.2.1 Nothing about us without us	No involvement as stakeholders in planning
			Procurements for the centres

Two categories were generated from this theme which were noticeable changes and care worker recommendations.

Category 2.1:Noticeable changes

Improved capability was a noticeable change for all the participants. Most care workers conveyed feelings of **appreciation for the LSPID learning programme** stating it was to them like sudden showers of rain during a dry despondent season. The care workers emphasised that they had no formal teaching and learning at the SCCs other than the care routine. They would teach any concept they deemed necessary, unguided on what content is suitable for the learners with SPID. The care workers acknowledged that some of their practices were incorrect mainly because they lacked knowledge and were not aware of the potential harm they could pose on the children. The care workers commended the training for bringing them the light and steering them towards corrected practices so they could identify some of the incorrect practices and instigate change.

"*We can now see that some of the things we were doing were wrong, we can now correct our practices according to the knowledge they have given us*" **(P8)**

"*It's like a whole new world that they have exposed us to, now we can see life in a different light*" **(P1)**

The care worker's wellbeing increased upon exposure to training on the learning programme for LSPID. The care workers expressed that their view and perception of working with disabled children has completely changed, as they described feelings of renewed strength and excitement of new possibilities that may arise as they are capacitated, fuelled, and better positioned for impact.

A **positive impact and influence of the LSPID learning programme** was perceived by the care workers on their wellbeing. They also experienced the programme as beneficial and effective for the learners with SPID and care workers experienced these children as less difficult to handle.

"*It has opened our eyes, and even the children enjoy the activities we engage them in, and they are happy with this new programme*" **(P9)**

"*There are children whom we did not know how to handle if we wanted them to sit and they refused or were roaming, but after the workshop, it has opened my eyes, now I know how to deal with such instances*" **(P10)**

On the one hand, the limited access to rehabilitation for the learners with SPID in SCCs was perceived to have improved with the presence of the educational outreach team. It was felt that the status of the SCCs changed through the provision of training on a formal programme thus benefiting the service users.

"*Before, there was nothing going on, but now, this looks like an educational facility (school), initially it did not look like that, serious(ly), to be honest*" **(P1)**

"*The role that LSPID plays is significant because you are a multidisciplinary team, a child gets speech therapy, physiotherapy and so forth, and it's great because you tell how to transfer the skill to the parent at home to ensure continuity* " **(P3)**

Category 2.2:Care workers input

On the other hand, the care workers expressed their feelings of **being undermined and the lack of their input into the running of the LSPID learning** They feel that decisions were made in their absence even though they are expected to do the groundwork and ensure the programme was delivered. A few of them questioned whether they were excluded from the planning processes due to their level of education. Furthermore, the care workers voiced that how they are not asked about the help they require. Their perceptions are suggestive of the experienced exclusions.

"*I will recommend that when they prepare to go do something, for the centres, like they say nothing about us without us, don't take decisions without us, don't want to buy something for me without consulting me, because I'm not going to be same as the next person, you might have bought it for someone else and it worked for them, but I'm not them, I am me and, I've got my own needs, so before you just decide for everything, ask for my opinion, on that particular thing, ask for my say on that particular thing, because now you just piling things on top of me, and for one, I have a question, how am I going to use all these things coz they don't even benefit me, and then if you find those things just sitting there, I'm in the wrong obviously, so you can't take such vital decisions without involving the people who are on the ground all the time*" **(P12)**

More than half of the participants were brave enough to express their dissatisfaction with **not being active participants in forums that plan and inform the practices of the for LSPID learning programme**. They also raised that they would like to be involved in the process of determining what resources were to be purchased for the SCCs.

"*With regards to food, the Department of Education provides food (to schools). May they please consider*

assisting the centres as well, even if they don't give us everything but perhaps give us only that which we mainly feed our kids, that too will help" **(P10)**

The care workers recommended that they too be capacitated to have slots in training/ workshops as trainers, as it will go a long way to have peer training - 'parent-to parent' or 'care worker to care worker.'

DISCUSSION

In this study, most care workers were female since care for children falls to women, as it entails activities traditionally ascribed to women such as feeding, bathing and toilet training[27]. The number of duties expected from care workers means they work long hours and have very busy days[12,28] with their services often limited to body care and provision of meals. The role of care worker is often fulfilled by women of low-socioeconomic status with low levels of education who are then further undervalued by inadequate training and poor renumeration[29,30]. In a study conducted in Western Cape Province of South Africa, educational qualifications of more than half care workers were Grade 10 or just above, which is similar to this study. The care workers have at most completed the home-based care course, basic training in first aid, seating and positioning as well as feeding, communication, stimulation, and play. Similar to the Western Cape care workers, the Mpumalanga care workers also receive minimal remuneration from the Department of Social Development[31]and none from the Department of Basic Education.Kaluski et al.[32] postulated that policies concerned with improving the quality of care must critically heed the care workers, especially their unmet expectations to ascertain that their needs are not disregarded over those of their clients.

The care workers highlighted that there is a discrepancy in their needs to offer good care and what the DBE offers. It was suggested that assistants were required to support the extra workload and the LSPID learning programme should only be implemented with an adequate care worker to child ratio of not more than 1:8[12]. This did not materialize in the SCCs in this study. Participants perceived that the DBE imposed extra responsibilities without any recognition or remuneration with no added support or appropriate resources. The priorities for the SCC were infrastructure and assistive devices; instead, they received therapy apparatus and teaching materials for which they do not have adequate storage as they are already operating in cramped spaces. However, infrastructure and assistive devices are the responsibilities of Department of Public Works, and Department of Health respectively. That means even if the DBE has funds available, it cannot assist with the priority needs, a concept which does not make sense to the care workers as government is one entity to them. The care workers find it unacceptable that the government departments with jurisdictions and authority are not collaborating and thus neglecting the core problems. Thus, thorough planning must be done,to indicate the clear financial responsibilities of each department to ensure continuity and sustainability of the programme[28]. Salojee et al.[33] reported a lack of collaboration in the major government sectors in the frontline of child disability and it is clear from this study that this impacts the successful implementation LSPID learning programme. The need for intersectoral collaboration cannot be over emphasised, the different departments of government need to take hands and work together and collaborate by clarifying the role of different sectors and ensuring uninterrupted service provision[12,34].

Even though the care workers would rather choose assistance of infrastructure and transport over education programmes and teacher learner materials, and they do acknowledge that their daily routines are now filled with a variety of activities, they also enjoy stimulating the learners. The learners experiencing fulfilment while at the centre and the activities they engage in, make the time at the centre worthwhile for both the care workers and the learners with SPID. Similar findings were reported by participants in the carer training conducted by Chocarro et al.[34] that they emerged skilled, knowledgeable and capacitated to promote child development. McKenzie et al.[12] emphasised that the education approach for children with SPID should move the focus from what the children cannot do and invest efforts on providing support for maximising participation.

The care workers experienced the LSPID learning programme as effective with regards to broadening their horizon with knowledge and servicing the children with rehabilitation and education, even though learners with SPID are likely to remain dependent in a number of areas and require high support[35]. Most care workers were enthusiastic about teaching the learners and recognised that the LSPID learning programme improved their knowledge and the activities they were trying to teach which had previously not necessarily been appropriate[12]. Although the programme did fulfil the aim to capacitate care workers the need for more support in the implementation of the programme, was also identified[6,18].

Salojee et al.[33] and Vergunst et al.[14] indicated that it was necessary to get qualified personnel to meet the basic needs of children with disabilities. Capacitating the care workers was used to alleviate the burden on the systems hence the LSPID learning programme invests time and resources in training and capacitating the care workers to upgrade the services rendered in the SCCs. Even though the care workers receive ongoing training this is unfortunately not designed and accredited to qualify their skills[12].. The care workers collectively agreed and feel that their level of education makes the professionals underrate and undermine their contribution, considering that they only receive in-service training that are not accredited with the national qualification framework from the DBE.

The learners with SPID in South Africa had limited access to education and rehabilitation services that include speech therapy, physiotherapy and occupational therapy[28]. The care workers described how they struggle with rehabilitation services in a rural, low economic settings and underserved part of South Africa. They expressed gratitude and appreciation over the relief that the LSPID learning programme has brought to them, especially now that multidisciplinary intervention has been brought to the children who could in no way afford it. Hence, the LSPID learning programme and outreach programmes are of high value to these underserved areas[36]. This explains the appreciation the care workers expressed over the programme availed to their SCCs by the education outreach team.

The care workers in their expressions bemoaned they were never included in any decision making. Overall, the care workers yearn for the principles of ownership and participation to be respected, they would like to make inputs and contributions and not only be on the receiving end as implementers[13,37] It is therefore important to sensitise service providers about their interactions over knowledge-sharing and information imparting which should incorporate service users in decision making platforms [38,39]. Excluding care workers in decision making emphases their sense of also not being viewed as important. Acknowledgement, through for example inclusion in decision making underscores a sense of being regarded with human dignity. Similar findings are reported by Conradie et al.[40] since more than half of the participants in this study expressed occupational stress due to lack of participation in decision making in relation to the LSPID learning programme. As a result, care workers actually feel dehumanised as described by Vandrevala and O'Dwyer[41] as their knowledge has been devalued by the service provider.

Not bringing the care workers on board and excluding the care workers in executive planning may affect the outcome of the LSPID learning programme as the care workers are the main role players who are expected to execute the strategies and activities. It is unrealistic to assume these roles can be filled by trained teachers[42]. There may be reluctance to follow through since the care workers are not active agents in the project and care workers feel like they have not actively influenced the decision-making process and outcomes.

Limitations of the study

The study was conducted in a very specific context focussed on a very specific programme. Thus, the findings are limited to this group of

people and may not be transferable to settings that are not contextually similar.

CONCLUSION

The study uncovered the mixed experiences of care workers involved in executing the programme for learners with SPID in Mpumalanga. On the positive side, the care workers appreciate the education and capacity-building aspects of the programme, which equip them for their roles. However, they express dissatisfaction with not being compensated for the additional job demands imposed by the DBE and perceive a gap between their actual needs and the assistance provided. The care workers view the project as requiring their service yet undermining them based on their level of education to make inputs and contribute on the vision and mission of the project.

Before evaluating the effectiveness of the training in SCCs for the LSPID learning programme, it's crucial to understand the care workers' expectations and their ability to apply the training in practice. Their perceptions are vital for improving their experience, as the success of the programme largely depends on their active participation and satisfaction.

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Author Contributions

Vallery Diale, Lebogang Maseko and Lyndsay Koch conceptualised the project and Vallery Diale collected the data and interpreted the data under supervision of Tania Rauch van der Merwe, Lebogang Maseko and Lyndsay Koch. Vallery Diale conceptualised and wrote the article which was edited and approved by all authors in all its drafts.

Conflict of interests

Authors have no conflicts of interest to declare

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