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Original Research

“Us versus Them”: is the voice of the community heard when planning communication screening programmes for preschoolers?

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ABSTRACT

Objectives: Community consultation is necessary to ensure the uptake and use of community-based screening intervention to detect early childhood disabilities, as its absence can result in poor service acceptance and usage. To document stakeholders' perspectives regarding planning a community-based communication disorder (an impairment in the ability to receive, send, process and comprehend concepts or verbal, non-verbal and graphic symbol systems) screening programmes for pre-schoolers.
Study design: This qualitative research design used purposive and random sampling to recruit 46 participants from eThekwini Municipality, South Africa. These stakeholders consisted of caregivers/parents of children who underwent screening for communication disorders, People who are Deaf, their parents, early childhood development practitioners, health professionals and government officials involved with children with disabilities. All participants were adults aged between 19 and 79 years, with an average age of 39.7 years.
Methods: Data was collected through focus group discussions and individual interviews, which were thematically analysed.
Results: The four emergent themes were screening approaches, methods, location and personnel. Service users expected greater access to screening and reliable tests to identify problems by trained personnel at sites within the community. Service providers preferred a targeted approach to screening with parental input. Task shifting and sharing were seen as a solution to address staff shortages and provide services at health facilities, as resource constraints made it challenging to provide outreach services.
Conclusion: Stakeholder engagement revealed diverging views between service users and providers, with implications for programme provision and uptake. There is a need for ongoing, inclusive discussion to ensure consensus during the planning stage, in order to render services that address issues of equity and accessibility for people with disabilities in marginalised communities.

Introduction

Early childhood disability is a public and societal concern that requires urgent and ongoing attention,[1] as it is estimated that over 240 million children live with disabilities globally.[2] There are 29.9 million children with disabilities in Western and Southern Africa[3] with over 2.1 million children in South Africa alone.[4,5] The early onset of disabilities hinders academic progress and the fulfilment of human potential,[6,7] affecting the child and family's quality of life, which in poor communities entrenches the cycle of poverty.[3]

Screening is defined as the identification of unrecognised disease or impairments through tests that can be applied quickly,[8] and is essential to identify and detect the presence of disability early in children's development to enable a prompt intervention and thereby prevent further disability. This has been shown to have a positive impact on prognosis,[9] and is possible due to the availability of various methods to detect disabilities, such as communication disorders (CDs). These conditions are defined as an impairment in the ability to receive, send, process, and comprehend concepts or verbal, non-verbal and graphic symbol systems, these challenges hindering normal development,[10] thus necessitating early identification.

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Delivering screening services can be achieved by systematically assessing all individuals within a specific population, or conducting targeted screening to a specific group of individuals with risk factors for specific conditions, such as children.[8,11] Identifying disabilities such as CDs can be achieved by directly assessing children using various tests or indirectly using parental questionnaires.[12,13] Screening is particularly impactful in deprived contexts and should be accessible for the most vulnerable and socially marginalised.[1,14,15]

In a resource-constrained environment, socio-economic factors, low levels of awareness,[16] poor governance and a lack of appropriately qualified personnel can have an impact on delivery, with these systemic barriers needing to be addressed to establish and sustain equitable service distribution and quality health care.[17,18] In Sub-Saharan Africa, the high burden of disease, especially communicable diseases such as HIV/AIDS,[19] has resulted in childhood disability being relegated to a low priority in health service planning.[20] Up to 40% of children in KwaZulu-Natal Province, South Africa, are born to mothers who are HIV positive,[21] and are therefore HIV exposed perinatally. Research has shown higher rates of abnormal central auditory pathways[22] and cognitive deficits[21] in HIV-exposed uninfected children, resulting in communication delays,[21] making early detection and rehabilitation essential in this newly identified cohort.

Early childhood development (ECD) centres are a government initiative to prepare children for school, these being accredited and registered organisations, with a varied number of pupils enrolled, that provide day-care services for babies, toddlers and children up to the age of five years.[23] ECD facilities vary in quality and operations with only 10% of practitioners or caregivers having a formal qualification higher than grade 12.[24] The economic inequalities in South Africa render access to quality ECD care a challenge, therefore, in order to optimize learning at ECD centres detection of disabilities is necessary to identify those who have barriers to early education.[25]

There remains an urgent need to address how community-based screening services are planned and delivered to maximise their effectiveness and acceptance in resource-constrained communities. It is essential that there are opportunities for the diverse input of all stakeholders through consultation and collaboration to ensure co-learning and shared decision-making,[26] this process being informed by Primary Health Care (PHC) principles.[27] This engagement is more likely to result in successful value-based care, with acceptance and good follow-up, than those that are planned without user input (people who directly benefit from the screening outcomes).[28] However, there is a lack of pre-emptive research documenting stakeholder views regarding the planning of early childhood disability screening programmes. There is a tendency to implement screening services without adequate consultation with service users and providers (health professionals and managers responsible for delivery of care), who seldom have the opportunity to deliberate on the design collectively.[26] This study therefore aimed to document stakeholders' perspectives regarding designing a community-based screening service to detect early childhood disabilities associated with communication disorders using a qualitative study design.[29]

Methods

Study design

The study entailed a descriptive, explanatory design using a qualitative approach[30] to engage and facilitate an understanding of stakeholders' views and recommendations about accessing and utilising screening services for preschool-age children.

Ethical consideration

Ethical clearance was obtained from the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (BREC 0000977/2020). Written permission was obtained from the KZN Department of Social Development (31/08/2020), Health (KZN202003_020) and Non-profit organisations (KZN Blind Deaf Society and Action in Autism), which renders services to people with disabilities. Written consent was obtained for all participants, their confidentiality and anonymity being ensured through the use of codes and pseudonyms.

Data collection methods and tools

Focus groups (FGs) and individual interviews (IDI) were used to obtain qualitative data[30,31] and the discussion guide consisting of two sections using open-ended questions[32] that were self-developed after consulting the literature.[31,33–35] The first section related to their socio-demographic details, while the second explored their definitions of screening, programme indicators (how the programme outcomes should be measured), screening protocols and recommendations relating to how best to implement the service. The guide was translated into isiZulu and then back-translated into English to ensure translation accuracy and content validity.[36] All the sessions were conducted in the participants' preferred language(s) and audio-recorded, lasting 45–90 minutes.

Study context description

The study was conducted in the high-density residential areas of Phoenix, Inanda, Ntuzuma and KwaMashu (PINK) in the eThekwini Municipality, with approximately 1.15 million people living in 22 km^2. This is one of the largest low-income households areas in eThekwini, with almost 77% earning less than the internationally recognised poverty line of $110.60 per month.[37] The main occupants are people of African and Indian descent, with isiZulu and English being the main spoken languages.[38] The majority of inhabitants make use of public sector health services, which are accessed through PHC clinics, at which patients are referred upwards for more specialised services, such as screening and intervention for CDs.

Sampling method and sample size

The study utilised a combination of non-probability purposive and random sampling to identify participants for inclusion.[30,39] The participants were grouped into two categories: service users (SU), these being people who directly benefit from the screening outcomes, and service providers (SP), who are health professionals and managers responsible for the delivery of care (Table 1). The service users are stakeholders, such as caregivers and parents (CG) of children affected by communication disorders, early childhood practitioners (ECDP), including teachers, whose services provision is directly impacted by children presenting with communication disorders. Service users are also People who are Deaf (PWD) due to communication disorders, and their parents (PPWD), who have lived experiences raising children detected through screening. Communication disorder screening entailed speech-language development and hearing assessments. Speech-language was assessed using the neuro-developmental questionnaire Ages and Stages 3 and hearing was tested using an otoscope, tympanometry, transient evoked otoacoustic emissions and conditioned play audiometry.[40]

Table 1
Participant code, group descriptions, and data collection methods.

Participant group	Code	Role in the study	Data collection method and sample size
Service Users			
Early childhood development practitioners (ECDP)	SU1	Educators and supervisors	1. ECD sites contact details obtained from DSD database. 2. 28 sites for CD screening were randomly selected. 3. 20 ECD practitioners participated. 4. Four focus group discussions consisted of 3–5 members each were conducted.
Caregivers (CG)	SU2	Parents/legal guardians of children who underwent screening	1. Sites contact details obtained from DSD database. 2. 28 ECD sites for screening randomly selected. 3. Seven caregivers attended FG
People who are Deaf (PWD)	SU 3	Adults who are Deaf or hard of hearing using Sign Language and aural communication.	1. Participants who are Deaf were recruited from KZN Blind and Deaf Society. 2. Participants contacted and invited to participate via short message system (SMS). 3. 4 individual interviews held at their homes, Sign Language used.
Parents of people who are deaf (PPWD)	SU4	Parents and legal guardians of participants who are Deaf	4 parents participated in individual interviews at their homes.
Service providers (SP)			
Health professionals: Department of Health (DoH) and non-profit organisations	SP1	Employees working in childhood disability.	1. Recruited via a database of employees working at the KZN Blind and Deaf society, Action in Autism and Department of Health. 2. 3 focus group discussions with 9 participants conducted via Zoom
Department of Social Development (DSD) official	SP2	DSD representatives working with childhood disability	1. KZN Director provided contact details of managers 2. Interviews held with 2 officials at their offices.

Data collection process

This entailed a multi-staged data collection process at ECD centres, as well as at people's homes, offices and via Zoom. ECDs were a focal point of this study as it was where children were screened, their parents/caregivers and ECDP were recruited. People who are Deaf, their parents, health professionals and managers from the same area were accessed for discussions and interviews to explore their perspectives regarding the screening service delivery for communication disorders.

The first step entailed accessing the eThekwini North District Social Development data base of all ECDs in the PINK area to map their geographical location, from 28 sites were selected at which communication disorder screening was conducted on the children. A database of sites and children who were screened was developed and organised by residential areas to enable the further selection of the ECDPs and the children's parents.

A systematic approach to sampling is not common in qualitative research[39] which was adopted to address recruitment bias to select ECDPs and parents/caregivers for the FGs. Site selection was carried out using random selection where the names of the 28 visited sites were written on separate slips, put in a container, shuffled and randomly picked out one by one (Table 1). From the selected sites, four FGs comprising of ECDP agreed to participate consisting of three to five participants per session which were held face to face. The same procedure was followed to select and invite 20 parents/caregivers of children who were screened for CDs with only 7 attending the face-to-face discussion.

The recruitment of people who are Deaf, health professionals, and officials used purposive sampling[41] (Table 1). The individual face-to-face interviews (IDI) were conducted with Deaf adults, with a Sign Language interpreter, and their parents at their homes, while the FG discussion with the service providers from the Department of Health (DoH) and non-profit organisation (NPO) (KZN Blind and Deaf Society and Autism in Action) were held via Zoom. For the Department of Social Development (DSD) managers/officials' interviews were carried out at their offices.

The study ensured credibility by the researcher adhering to the FG and IDI guides, which were piloted before data collection. Dependability was ensured through detailed descriptions of the study protocol, notes captured during the sessions, and data collection analysis used methods such as a coding book [supplementary file-A]. Member checking was conducted to ensure that the responses were captured correctly and the data was dependable.[42,43]

Data analysis

The data from all the recorded FG discussions and interviews were transcribed verbatim, translated into English where necessary, and analysed thematically to enable data triangulation. The thematic analysis consisted of five stages, the first being repeated careful reading to enable data emersion and loading the written text into NVivo (version 12) software, which undertook the analysis.[44] Stage two consisted of the coded words and sentences related to interventions for childhood communication disorders in pre-schoolers identified by the software being assigned descriptive labels. Stage three entailed grouping the codes to identify patterns and relationships,[45] in stage four, the codes were clustered, initial maps were formulated, and overarching themes reviewed for coherence through thematic maps, and stage five entailed refinement and presenting the data. The data from each interview and FG was analysed separately and the data triangulated into a composite set on completion to identify similar and different opinions both within and between the users and providers.

Results

Of the 46 participants, 40 spoke isiZulu, their ages ranged from 19 to 79 years (average age of 39.7 years), and the majority ($n = 42$) were females, with the data for the service users and providers being presented in Table 2.

Four themes emerged: screening approaches, methods, location and personnel, which are visualised below in Fig. 1, as a thematic map.

Table 2
Participant profile of service users (SU) and service providers (SP) and Description.

Category	Variable	No	Category	Variable	No.
SERVICE USERS (SU)					
Early childhood development (SU 1) practitioners ($n = 20$)					
Ethnic group	African	19	Position	Supervisors	4
	Indian	1		Educators	12
Gender	Male	0		Support Staff	4
	Female	20	Experience	Years	1–45
Age	Years	20–70		Average years	8.2
	Average	36.5	Qualifications	NQF 4	15
Education	Grade 12	20		NQF 5	3
				NQF 6	2
Caregiver of children screened (SU2) ($n = 7$)					
Ethnic group	African	7	Ages	Age range	19–50
Gender	Male	1		Average age	33
	Female	6	Employment status	Self-employed	1
				Employed	4
				Unemployed	2
People who are Deaf (SU 3 ($n = 4$)					
Ethnic group	African	4	Education	Grade 12	4
Age	Age range	23–38	Employment	Employed	4
	Average age	33.5		Unemployed	0
Parents of people who are Deaf SU 4 ($n = 4$)					
Ethnic group	African	4	Employment status	Unemployed	4
Gender	Male	1	Financial income	Social grant	4
	Female	3	Education	Grade 6	2
Age	Age range	60–79		Grade 12	2
	Average age	67			
SERVICE PROVIDERS (SP)					
Health professional's SP 1 ($n = 9$)					
Ethnic group	African	4	Discipline	Audiologist	3
	Indian	5		Clinical psychologist	1
Age	Age range	28–48		Occupational therapist	1
	Average age	35.5		Social worker	3
Gender	Male	0		Speech-language therapist	2
	Female	9			
Department of Social Development official's SP 2 (Social workers who supervise ECD) ($n = 2$)					
Ethnic group	African	2	Experience	Years	8–15
Gender	Male	1		Average	11.5
	Female	1	Age	Age range	33–36
				Average age	34.5

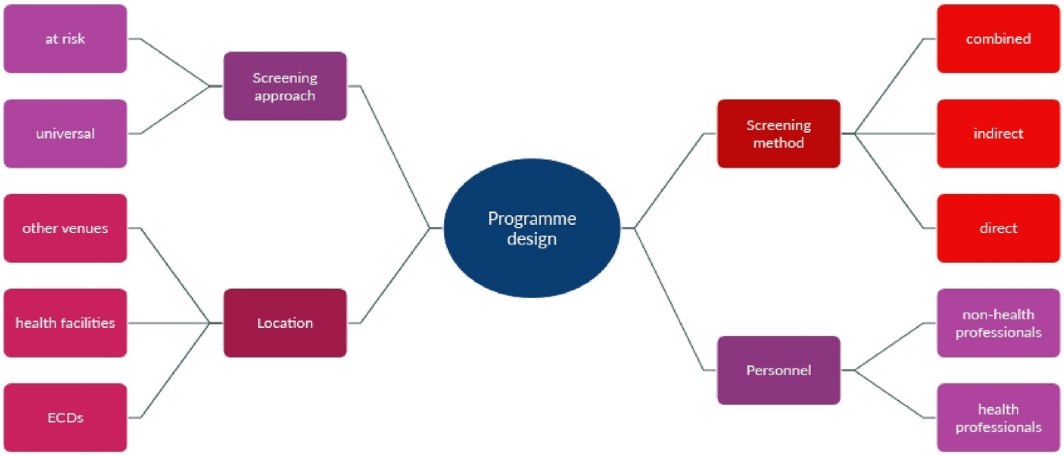

Fig. 1. Thematic map visualisation

Theme 1: Screening approaches

The two screening approaches for detecting disorders including communication, are universal or population-based and targeted, each appropriate for different situations.[8] The majority of stakeholders ($n = 31$) voiced a preference for population-based communication screening as the most suitable approach to detect children with CD, as it is not conducted at primary healthcare (PHC) facilities. Patients requiring such services need to obtain a referral letter from the PHC that enables them to access district-level hospital outpatient clinics for more specialised care. This view is informed by acknowledging the need to overcome the challenges in accessing community-level rehabilitation services, with good agreement between the FG and IDI service users, specifically people who are Deaf and caregivers of children who received the service.

> *"… you will find the children in numbers, and the children will be able to get the help they need"* (SU4 SS 60yrs, parent of a person who is Deaf). IDI

> *"Test all the children at creches to pick up those with problems which would be missed if the screening did not take place"* (SU2 EK1 35yrs caregiver of children screened). FG

However, the service providers, mainly health professionals, preferred targeted screening at health facilities, citing limited resources, as they are busy at the clinics and need more staff and equipment to provide additional services at outreach sites, such as ECD centres, with quotes from SP1.

> *"…Targeted screening is better because we use it to identify those at risks"* (SP1 SLT1 30yrs health professional, 7 yrs' experience) FG

> *"Population or screening all the kids at creches is not possible with shortages of staff"* (SP1 SLT2 47-yrs health professional, 20 yrs' experience) FG

There was some consensus among the participants regarding the approach to providing community screening services with the intention to reach a wider population despite the logistics and resources challenges.

Theme 2: Screening methods

Screening can be conducted either directly (physically assessing the child) or indirectly (through parental questionnaires) methods, as a means of detecting disabilities.[46] Most service users and some providers ($n = 23$) preferred direct screening by professionals, despite their concerns regarding the difficulties related to the cooperation and responsiveness of young children to undertake the tests. All people who are Deaf (SU4) supported direct testing, as they trusted the health professional's judgement over the caregivers' evaluation. There was concern that the parents' lack of objectivity regarding their child's functional abilities can lead to biased reporting, given the tendency of some family members to deny the existence of this condition. There was good agreement between people who are Deaf, their parents and caregivers of children who underwent screening regarding the method of screening preschoolers.

> *"I prefer the one where you come physically to screen the child"* (SU3 SS 26 yrs person who is Deaf). IDI

> *"I prefer the one where you come physically to screen the children. When you come here, you will be able to identify the child; it is not the same as what is written on paper" (SU4- AS 79 yrs parent of person who is Deaf). IDI*

Concerns were raised about indirect methods, such as questionnaires, as parents may be uncomfortable disclosing their children's difficulties and fear that they might experience stigma, discrimination, marginalisation or be ill-treated and victimised. Other concerns from service users and providers relating to literacy levels in poor communities if questionnaires were used for screening, as most are in English and seldom translated into all vernacular, compromising their accurate completion. There was good agreement between the person who is Deaf and ECDPs regarding the preference to directly screen based on their concerns relating to the discrepancy between questionnaire reports and direct screening outcomes.

> *"When you come here, you will be able to identify the child's problem, which is not the same as what is written on paper"* (SU3 AS 44yrs, person who is Deaf). IDI

> *"The reason why they do that is they want their child to seem perfect. If the parents say that there is a problem with the child, she fears that the child might be discriminated against, so it is better to diagnose if there is a problem.* (S32-Q1 29yrs, caregiver). FG

> *"If they find the time or not to fill them, because you find parents may face challenges at work, and sometimes you may just find it is the parent's negligence" (*SU1- *BB2 52yrs old ECDP with 10yrs experience).* FG

Some ECD practitioners and service providers ($n = 15$) preferred indirect screening, using caregivers' responses to questionnaire to identify disorders, as direct screening was perceived to be labour-intensive and time-consuming, a problem when a staff shortage prevails. They were concerned about children not responding appropriately to the tests due to a fear of strangers and a limited attention span. They also cited the limitations of available screening equipment, which resulted in slow testing efficiency, and felt that parental feedback could provide insight into their child's ability. There was some agreement between the health professionals and caregivers of children screened regarding direct screening concerns in the current context. The disparity between the views is that health providers focused on equipment limitation while the caregiver reported on the parental concerns to admit that there is a chance of their child having difficulties that need further investigations.

> "*Still, if you are going to be screening, you know the devices are not developed for South African population and context they are costly. They are often time-consuming, and we want to get through as much of the population as possible. (SP SLT 47yrs health professional with 20 yrs experience). FG*

> "*And also the attention span is very low so that you wouldn't keep the child for a test for 30 minutes they will end up being distracted and then we'll just end up saying yes, or no, just to get through the test." (SP1 SW2 39yrs health professional with 13 yrs experience). FG*

> "*....because the parent would write what they have seen in their child. I don't think they would lie about it." (PWD NZ 26yrs old) IDI*

A few participants ($n = 8$) opted for the combined approach using a two-tier strategy, the parental questionnaires being conducted as baseline screening, followed by direct screening to confirm the responses. This suggestion was introduced as an alternative to be considered due to the contextual challenges mentioned earlier.

> *"So, a combination of using a parental questionnaire. Then I guess our standardised tests and scores* … (SP1 Clin. P 42yrs health professional with 15 yrs experience). FG

> *"I think it would be better if you use both methods, because those who cannot make it on that day can still fill the form, and it would be up to them" (SU1 BB3 49yrs ECDP with 13yrs experience).* FG

Some health professionals did not agree with the combined approach to screening, noting that a questionnaire was not necessary as they would use their expertise in the screening to interpret the outcomes. The ECDP's suggestion to use the combination method was influenced by the difficulties of conducting screening using questionnaires in a language that the respondent may not be familiar with or wanted to hide the true status.

Theme 3: Screening location

Most participants felt the need for screening to be conducted at ECD centres rather than only being available through the overcrowded PHC facilities where they had to wait for referrals to access rehabilitation services at the district hospital, which were far from their homes, and entailed long waiting times. Parents leave their children at the ECD centres close to where they live while they attend to other commitments, with screening at these sites enabling many children to be reached in a familiar environment, reducing their fear and anxiety about the tests. There was consensus between the two FG responses regarding the convenience of screening at ECDS for parents.

> *"It is better to have them screened in crèches, because that is where children meet, and you get them in numbers."* (SU 1 I2 39yrs ECDP with 5yrs experience). FG
>
> *"I think it is better to do it at the creches, because parents are too lazy to take the child to the clinic. Hence, I say it is better here, because this is where children are always. Even when the children have to go for vaccinations, the parents are too lazy to go to the clinic because of long queues, so they prefer mobile clinics. This initiative will be more organised." (SU 1 S3 31yrs ECDP with 5yrs experience). FG*

Only a few caregivers, ECD staff and health professionals ($n = 4$) felt that screening should not occur at ECD but at health facilities and other venues, such as community halls, as they are clean and could accommodate the various screening equipment and staff required, given that some ECD centres are very small. All participants felt that screening should be performed quarterly among preschool children to monitor any changes. There was no agreement between the IDI and FG responses on the proposed alternative location, with the parent of a person who is Deaf opting for health facilities, as they are resourced, while health professionals opted for community halls for accessibility.

> *"I prefer hospitals because they are clean and have all the resources nearby"* (SU4 SS 60yrs parent of a person who is Deaf). IDI
>
> "*The Community hall is the best place." (SP KZNBDSW 3 27yrs health profession with 4yrs)*. FG
>
> "*……quarterly to see if there are any changes or progress"* (SU1 S2 55yrs ECDP with 9yrs experience). FG

Theme 4: Screening personnel

The service users felt that health professionals were the most suitable cadre to conduct screening, with a preference for Audiologists and Speech-Language Therapists over nurses and doctors, the latter being perceived to be overwhelmed by the workload and their expertise being less than that of the rehabilitation personnel.

> *"I would say therapists, because they are qualified in this field; they will be able to see if a child has a problem, and I think it would be faster"* (SU1 E3 45yrs old ECP with 10yrs experience). FG
>
> "For *the nurses, I would say, taking into account their workload, maybe it would not be feasible for them to go out there"* (SP 1 SW1 47yrs old health professional with 20 yrs experience). FG

Some service users and health professionals ($n = 8$) opted for nurses, mid-level workers (MLW) and Community Health Workers (CHW) to conduct the screening, but felt that more staff needs to be employed as they also have to provide other essential services. They preferred a programme leader who was a qualified health professional to oversee specialised services, with some service provider participants reporting a high personnel turnover, resulting in human resource shortages due to vacant posts, with additional posts needed to make screening services accessible to the public. CHWs are known in their communities and were not regarded as suitable as they could compromise confidentiality if a child was found to have hearing problems, while others felt that they lacked expertise with CDs and would need to be particularly patient with young children to investigate such conditions. The already overburdened nurses were not regarded as ideal for screening as their time pressures might compromise the quality of service. There was good agreement between the health professionals, caregivers and EDCP regarding the preference not to use non-health specialist. There was a low level of agreement between the different health professionals, ECDP, and caregivers regarding the CHW conducting screening due to the existing staff shortages.

> "*If you are short of staff, then yeah, you can train a community health care nurse…"* (SP 1 Aud2 30yrs heath professional with 9 yrs' experience). FG
>
> "*I guess it can be the community health care workers because they are used to visiting people's homes and detecting any problems"* (SU 1 S1 45yrs ECDP 10yrs experience). FG
>
> "*… .it is better if that person with the knowledge about this, unlike a person who is second-guessing or who would take it lightly, and some would not have the patience, but a person with experience would be able to look into detail."* (SU 2 EK3 35yrs parent of children screened). FG
>
> "*You cannot just take anyone and think that they will do the screening, but what if they misunderstand…. if a specialist does it, there is a guarantee that the child has a problem, because they are talking about what they know to see that the child has a problem"* (SP 2 SW2 39yrs health professional with 13 years' experience). FG.

Discussion

This study aimed to document stakeholders' perspectives in planning a community-based screening programme to detect communication disorders in preschoolers. This study was conducted within a healthcare system struggling with the early identification of children at risk for developmental disabilities.[47]

Barriers to implementation include the effective integration of programmes within existing infrastructure, costs, limited human resources, access and adequate engagement of stakeholders.[48,49] This is exacerbated by a healthcare system grappling with a quadruple disease burden of the increased prevalence of communicable diseases (HIV and TB), maternal and child mortality, noncommunicable diseases, and trauma.[50] Sadly, this backdrop has rendered children with communication disorders vulnerable to inadequate care and detection for rehabilitation.[51] These abovementioned systemic problems suggest a greater urgency for universal surveillance to include adaptable screening programmes for pre-schoolers,[48] especially in impoverished communities[52] with complex socio-economic factors[53] associated with a high prevalence of communicable disease.[54]

Compliance and uptake within afflicted communities are crucial to the success of such programmes and could be challenging without appreciating stakeholder views.[55] Unfortunately, service users' voice remain largely unheard during stakeholder engagement, particularly pre-schoolers with disabilities, the most vulnerable in poor communities, who have many access barriers.[34]

Four critical findings on planning a community screening programme were reflected in the participant's responses relating to screening approach, methods, location and personnel. The differing views reflected their experiences as users and providers, with few opportunities for engaging and understanding each other.[56] An international survey by Darzi[34] aimed to assess stakeholder's perceived feasibility and acceptability of 18 rehabilitation services and values attached to 10 rehabilitation outcomes. They reported the need for including people with disabilities in the decision-making and more community-based rehabilitation that is not led by health professionals being established. Similarly, Papp conducted a study in Europe, where stakeholders discussed quality criteria between patients and health professionals, with divergent views[56] on service delivery expectations. However, both these studies health professionals (64%) were the majority who were service providers from developed countries with different health priorities than developing contexts. There is a need for studies where service users are in the majority, necessitating the current study.

The inclusion of five sets of participants gave a broad overview of people using and providing such services, this being important when planning an intervention for people from poor socio-economic backgrounds who do not have the means to pay for private health care.[34] As the majority of South African residents rely on public sector health services,[57] ensuring that they are available, accessible and affordable should be a priority, specifically for people with disabilities. However, understanding the limitations within which government officials and employees operate is equally important,[35] as it is not always possible to provide the required services where they are needed in a manner that is acceptable. Canvassing the opinions of relevant stakeholders is therefore essential if appropriate compromises are to be made and accepted, hence the inclusion of the various groups in this study.

Theme 1: Screening approach

Service users voiced dissatisfaction with the targeted approach currently used to assess children with disabilities at PHC facilities, and contended that a universal approach would enable better coverage and opportunity to detect those who could be missed due to having subtle impairments. This view proposed that early detection services should focus on the entire population rather than a sample, as supported by local studies, where universal screening was deemed feasible, although resource constraints needed to be carefully considered even though these studies were conducted on newborns, they echo similar assertions.[48,58] However, service providers advocated for targeted screening due to their experiences of a healthcare system struggling to meet population demands, thereby preventing the additional pressure on the already constrained staff and resources, as suggested by local studies on newborn hearing screening.[59,60] This dichotomy in stakeholder views reflected the diverse aspects that need to be carefully addressed to ensure service acceptance. It was recommended that a population-based approach be adopted, as it allows for all children to be screened, given that rehabilitation service accessibility remains a challenge, particularly in impoverished communities,[35] and enables access to early intervention and reduces healthcare access barriers.

Theme 2: Screening methods

Service users preferred direct screening, one of three available screening methods, due to their desire for an accurate assessment to inform the diagnosis.[61] Service user concerns over the indirect methods, such as questionnaires, were influenced by challenges such as low literacy and limited English competency, which could affect the response accuracy and completeness. Studies have reported that 4.4 million (11%) adults were regarded as being illiterate in South Africa in 2021, particularly older generations.[62,63] Poor parental follow-up of questionnaires has been reported as a challenge, especially in low socio-economic families,[64] as reported by an international study that conducted a systematic review and provided global prevalence data. Those supporting this method of indirect screening, in the literature are from a predominantly developing context,[65,66] rationalised it as being easy to administer, cost-effective and therefore suitable in areas with limited resources, as reported by other studies,[13,67,68] with parental input being valuable for diagnosis. It has been suggested that in contexts without universal health care coverage direct screening, using questionnaires will enable screening to reach many children at a reduced cost and require fewer highly skilled professionals, as suggested by studies from contexts similar to South Africa.[67–69] Some participants advocated for a combined approach, the initial step being a questionnaire to identify at-risk patients, this being confirmed with direct screening linked to intervention for those at risk.

Theme 3: Screening location

Most participants supported locating screening services at ECDs, not at PHC facilities, preferring professionals to be accessible and closer to the community, with many having work commitments that do not accommodate time off to attend clinics. The participants did acknowledge that the ECD infrastructure, especially in poor communities, could be improved, and may not be big enough or have the necessary infrastructure to support screening activities.

The international practice of screening for communication disorders at ECDs was reported as early as 2004[70] from developed contexts. In contrast, there was a call for implementing screening programmes in developing contexts as early as 1992,[71] with several challenges rendering implementation difficult, including the availability of rehabilitation services and resources, such as in South Africa and Malawi.[72] To keep abreast with international trends for screening at ECDs, developing countries, such as China[73] and South Africa, have started reporting on their progress at such venues.[74,75]

Of note is that service providers preferred services to be located at a PHC facility as they are better equipped. Pillay[76] highlighted chronic health personnel shortages, which are prevalent in the majority of developing contexts, including South Africa, hence the limited availability of outreach services, particularly for rehabilitation to detect communication disorders. These limitations made it challenging to provide outreach to ECD centres or community halls, with high work pressure leading to staff burnout and reduced public satisfaction,[77] a similar reality reported in South Africa due to chronic staff shortages. These participants recommended that screening services be located at ECDs due to the need to take them to where people can most conveniently accessible.

Theme 4: Screening personnel

This study found that service users preferred health professionals over non-health professionals to deliver screening, as they felt this would provide them with accurate and timely identification and intervention. However, Bright in Malawi,[78] reported that non-health professionals' testing accuracy for pure tone hearing screening was competent although they did not have qualifications. This did not prevent them from carrying out pure tone for hearing assessment after sufficient training. On the contrary, the service providers were open to non-professionals conducting screening due to staff shortages, as echoed by Darzi[34] and Louw,[35] who reported that rehabilitation services are hampered by the shortage of health specialists, which is a concern in many poorly resourced countries, particularly as rehabilitation staff,[79] with service demands often exceeding the services provided in the public sector healthcare system.[76] To alleviate the staff shortages and make services accessible, non-specialist healthcare workers, such as volunteers, community healthcare workers (CHWs) and ECD practitioners, could potentially close the skills gap.[80,81] Task shifting from specialist to non-specialist services will require training using technology-based platforms to undertake assessments and specific interventions, which will then scale up to health professionals for diagnosis and intervention, as supported by findings from Malawi and South Africa.[78,80] Thus, with appropriate training, ECDP is another cadre that could assist with screening, as they are frontline, and have easy access to pre-school children.

Several limitations may have affected the results, such as some participants living in the low socio-economic PINK area, limiting generalisation to the other resource-constrained populations, including rural areas, where ECDs may not be available. It is recommended that future research be carried out in other parts of the country with varied social, economic and educational conditions that rely on the public and private health care sector to extend and broaden the findings and facilitate generalisation elsewhere. However, it is one of the few studies we are aware of in the discipline of communication disorders that has described the engagement of multiple stakeholders' views on service programme planning from a developing context within the public health domain.

Conclusion

In order to provide screening services that are deemed acceptable for pre-schoolers, all stakeholder views regarding the intervention must be understood to better comprehend the factors that improve acceptance and use of the services. During engagement, it is essential to allow all stakeholder to share their views, although consensus would be ideal, accommodating differing opinions at different times as it may provide optimal conditions for solutions to be raised that meet most people's needs. It is also important to shift the current narrative by elevating the service user's voice, including the impoverished, to enable them to have the same prominence as service providers during the design of public health intervention programmes. Health professionals must carefully plan service provision to be informed by the users' needs, above the convenience of the providers, especially when human resources are limited and shrinking.

This study's findings indicate that users are calling for a change in the current design of screening services, arguing for a shift from targeted health facility-based assessments to a population-based approach, with combined (direct and indirect) methods to screen and identify preschoolers with disabilities including CDs. Furthermore, a call to provide services at locations accessible for the users, such as the ECD or community halls, needs to be standard practice. Task shifting from health professionals to non-health professionals, or different cadres of health practitioners, should be facilitated to ensure broader coverage. In addition, this approach to designing screening programmes to detect preschool communication disorders can be transferred to other childhood disabilities. The call for a change in screening services is essential in resource-constrained environments with competing priorities that rely on developing a solid preventative care backbone in the public sector. An effectively designed programme will ensure that people make use of the services, specifically the most vulnerable, those with disabilities, whose quality of life will change for the better in the short and long term if their needs are met at such an early age.

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Competing interests

There is no conflict to disclose.

Author contribution

VZP conducted the interviews, analysing of the data, conceptualisation and write-up of the manuscript.

PR contributed the conceptualising and revising the manuscript.

MP contributed to conceptualising the manuscript and supervising the study.

YS contributed to conceptualising the manuscript and supervising the study.

Appendix A. Supplementary data

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