Communication skills, resources and needs of adults with intellectual disability in residential facilities in the Western Cape and their support staff: A descriptive study

by

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ABSTRACT

Many adults with intellectual disability are unable to meet their everyday communication needs due to various communication difficulties. Opportunities for meaningful social interactions, self-determination and community participation are thus significantly restricted. Support staff working within residential facilities for adults with intellectual disability play an important role in facilitating and interpreting the adult's communication as staff frequently interact with the adults. Studies have found that AAC strategies and tools prove effective in supporting the understanding and use of language in adults with ID, however the success of AAC intervention rests on the extent to which it is implemented and maintained by those interacting with and supporting them. The aim of this research is to describe the communication skills, resources and needs of adults with intellectual disability living in residential facilities in the Western Cape and their support staff, as reported by facility managers. Managers of 19 residential facilities for adults with ID in the Western Cape agreed to complete a self-administered questionnaire. The questionnaire was developed based on a range of both local and international previous studies and aimed to gain information pertaining to the (1) background of the facility and adults (2) communication- and related skills of the adults (3) communication skills of the care staff working directly with the adults as well as (4) current availability of communication-related resources and support for the adults and staff. The results obtained indicated that approximately a third of nearly 1000 adults with ID were unable to communicate effectively. Adults with no or limited functional speech most often relied on informal, unaided AAC strategies to communicate requiring interpretation from the care staff. Facility managers reported most care staff used a variety of practices that facilitated communication. Furthermore, aided and unaided AAC strategies and tools to support comprehension were implemented by some of the facilities which were obtained from individuals or organisations knowledgeable in AAC. However, few facilities implemented a formal mode of aided or unaided AAC to support expressive language due to a variety of environmental barriers relating to a lack of staff skill and knowledge as well as limited access to appropriate professions such as speech-language therapy for AAC related training or support. More than three quarters of participants indicated that was some or an extensive need for training pertaining to communication support. Broadly, a need exists for (1) aided AAC to support the comprehension and expression of language for adults with ID in residential facilities (2) staff to obtain knowledge and skills in more formal AAC strategies through ongoing training as well as (3) access to professionals who are knowledgeable and

skilled in AAC to provide individualised support to the adults and guidance to the multi-disciplinary team supporting the communication skills of the adults.

Keywords: Adults, augmentative and alternative communication, intellectual disability, residential facilities, staff communication support, Western Cape.

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1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1 Introduction

For many adults with intellectual disability (ID), impairment in conceptual and social domains of intellectual functioning results in complex communication needs (CCN) (American Association on Intellectual and Developmental Disabilities [AAIDD], 2019; Beukelman & Mirenda, 2013) Individuals with CCN experience severe communication impairment potentially affecting both the comprehension and production of speech and language. If daily communication needs are not being met, access to meaningful interactions and community participation may be limited for adults with ID (Beukelman & Mirenda, 2013).

Communication support such as Augmentative and Alternative Communication (AAC) offers a means of communication for persons with communication impairment by supplementing or substituting natural speech through the implementation of devices, strategies or tools (Beukelman & Mirenda, 2013). AAC has shown promising results for adults with ID (Sutherland et al., 2014). The success of AAC strategies or systems however rest on the extent to which it is implemented and maintained by those supporting or caring for persons with CCN (Dalton & Sweeney, 2013).

Historically, adults with ID in South Africa were placed in medical institutions, segregated from society with limited opportunities for engagement in their communities (Kock, 2009). However, the implementation of South African government policies such as the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2015) and the Integrated National Disability Strategy (INDS) (Office of the Deputy President, 1997) has promoted the social inclusion and daily life participation of adults with disabilities in communities and also allowed for more opportunities for self-determination. Consequently, adults with ID are transitioning from long-term hospital care to community-based residential facilities (Atkinson & Walmsley, 2010; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009).

Support staff within residential facilities; that is, individuals who provide care or services to with adults with ID (e.g., care staff, nurses and therapists) prove important in the facilitation of communication as they play an essential role in ensuring appropriate communication supports are in place (Dalton & Sweeney, 2013). Communication supports

encompass AAC systems, resources and partner strategies used to promote and facilitate effective communication. Additionally, care staff present as frequent communication partners for adults with ID, facilitating interpersonal exchanges to determine their needs and desires as well as providing opportunities for social interaction (Dalton & Sweeney, 2013). However, without knowledge and skills related to communication support or the availability of AAC resources such as assistive technology, staff cannot always provide appropriate communication supports (Dalton & Sweeney, 2010, 2013).

By identifying and describing the communication and related skills of adults with ID, we can attempt to develop descriptions of this population and determine the prevalence of persons with complex communication needs (CCN) within residential facilities in the Western Cape. Furthermore, exploring how the support staff communicate with adults with ID can inform us as to whether the current knowledge and skills of the staff and the availability of AAC resources present as barriers or facilitators to effective communication support. We can also identify how their knowledge and skills can be improved to better facilitate the communication skills of these individuals.

Both internationally and within South Africa, a gap exists between best practice standards and clinical implementation regarding communication-related service provision for adults with ID (Dalton & Sweeney, 2013; McKenzie , Adnams, & Mcconkey, 2014). The information gained through this study will bring awareness regarding the communication and related needs of these individuals who are unable to express their own needs through speech as well as determine what is lacking in terms of AAC service provision within this context.

In order to provide additional background to the study, the following topics will be briefly discussed: (1) definition, prevalence and causality of ID; (2) models of disability and legislative frameworks (3) residential facilities for adults with ID in the Western Cape; and (4) communication supports for adults with ID.

1.2 Intellectual disability: Definition, prevalence and causality

ID is characterized by the American Association of Intellectual and Developmental Disabilities (AAIDD) (2019) as “significant limitations in both intellectual functioning and adaptive behaviour” which is present before the age of 18. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines ID as an IQ of approximately 70 or below on an individually administered standardised test of intelligence concurrent with impairment in

adaptive functioning (i.e. competence to perform daily activities required for personal and social sufficiency) (American Psychiatric Association [APA], 2013). Areas of impairment in adaptive functioning may include; communication, self-care, home living, social or interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety (Patel et al., 2010).

Based on the level of impairment in both domains, the severity of ID can be indicated as mild, moderate, severe or profound requiring varying support needs (AAIDD, 2019). In current research and practise, increasing emphasis is placed on the adaptive functioning rather than intellectual functioning when determining the severity of ID (Dennis, Forgeron, Morgan, St-denis, & Martin, 2016). Individuals with a mildly reduced intelligence quotient (IQ) score but substantially limited adaptive behaviour skills can be described as having a severe disability. Those supporting individuals with ID within a family or residential setting thus play an essential role in facilitating and developing their adaptive skills in order to maximise their independence in daily life activities and participation in the community.

ID is considered a chronic condition that often co-exists with other physical and / or mental health conditions such as cerebral palsy, epilepsy, depression, attention deficit hyperactivity disorder, hearing loss, Down syndrome, Fragile X syndrome and autism (Patel et al., 2010). Additionally, persons with ID and communication impairment are at higher risk of acquiring physical and mental conditions due to an inability to communicate health-related needs (Njenga, 2009). Mental health disorders are particularly prevalent in this population, and significant communication challenges paired with limited social networks often result in depression and loneliness amongst adults with ID (Fredheim, Haavet, Danbolt, Kjønsberg, & Lien, 2013; Hajjar, 2017).

The estimated prevalence of ID ranges from 2 - 3% of the world's population, varying in severity (Patel et al., 2010). Although inquest has been made into the prevalence of ID in South Africa, the exact prevalence figure is unknown due to ambiguity in census questionnaires, inconsistency in terminology, changes in classification systems and a paucity of published literature on ID in South Africa (Adnams, 2010; Foskett, 2014). Extrapolated research however suggests that South Africa exceeds ID prevalence in high-income countries, affecting up to 3.6% of the population and existing as "one of the largest impairment groupings in Africa" (Capri et al., 2018; McKenzie et al., 2014, p.46).

Evidence suggests that factors experienced by low and middle income (LAMI) countries such as poverty, malnutrition, poor education and a lack of healthcare and support services contribute to the particularly high prevalence of ID in South Africa (Adnams, 2010; Foskett, 2014; McKenzie et al., 2013). Adnams (2010) further suggested that causality of ID in South Africa is particularly associated with contextual events occurring during the prenatal and developmental periods of life such as nutritional deficiencies, HIV/AIDS, tuberculous meningitis (TBM), violence and injury, and fetal alcohol spectrum disorder (FASD), all of which occur commonly in SA.

In the Western Cape province, Kleintjes et al. (2006) estimated the prevalence of ID at 3.05% of the population at the time of their study. Of the total amount, 2.5% of adults with ID were identified as having a mild intellectual disability, 0.4% moderate, and 0.15% severe (Kleintjes et al., 2006). McKenzie et al. (2014) later extrapolated that there were approximately 108, 000 adults over 18 with ID in the Western Cape resulting from various developmental and acquired etiologies. Prevalence proves particularly relevant for this study in order to quantify the population who could potentially benefit from AAC interventions.

1.3 Models of disability and legislative framework

Prior to the late twentieth century, ID was understood from the perspective of a medical model of disability; individuals with ID were viewed as a flawed, requiring expertise medical intervention to treat their 'problem', preferably in a contained setting (Atkinson & Walmsley, 2010, p. 274). Institutions were subsequently created, resulting in isolation and segregation of persons with ID from the community, exacerbating societal prejudice (Verdonschot et al., 2009). During the 1970s, advocacy and human rights groups were formed in high-income countries, such as the United Kingdom and the United States of America, advocating for equality and political standpoints on the topic of intellectual disability transformed (Atkinson & Walmsley, 2010).

Service delivery for persons with ID with regards to the provision of medical and rehabilitative services as well as living arrangements consequently improved from the 1970s (Bach, 2007). Through the international establishment of a rights-based ethos and person-centred approach to service delivery for person with ID, perspectives of ID shifted from that of a medical model of disability to a social model which recognises that disability exists as a

result of societal constructs rather than as a medical impairment (Atkinson & Walmsley, 2010; Retief & Letšosa, 2018).

A similar transition towards a social model of disability occurred in South Africa as developments at an international level influenced how disability was understood locally (Retief & Letšosa, 2018). Through the implementation of a transformation agenda for marginalised and vulnerable persons, the Office on the Status of Persons with Disabilities (OSPD) was formally established in 1997 and the White Paper on an Integrated National Disability Strategy (INDS) was subsequently released (Office of the Deputy President, 1997). The INDS is rooted in a social model of disability as its key features encompass full participation, inclusion and acceptance into society, acknowledgement of disability as a societal construct and improving quality of life of persons with disabilities (Office of the Deputy President, 1997).

Similar to the INDS, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) views societal constructs such as environmental constraints and negative attitudes as obstacles to the full realisation of human rights for persons with disabilities (United Nations, 2006). The UNCRPD, of which South Africa is a signatory, defines and applies existing human rights principles to persons with disabilities and exists as a framework to contrast desired standards against existing provision (Stainton & Clare, 2012). The current study is congruent with the social model of disability and consequently the INDS and UNCRPD as is it concerned with identifying and describing communicative barriers to participation experienced by adults with ID as a result of the interaction between the adults and their environment. Understanding these barriers is the first step in planning programs to address them, with the ultimate goal of improving the adults quality of life.

The International Classification of Functioning Disability and Health (ICF) and similarly the Participation Model for AAC can be used to identify and describe such environmental barriers experienced by adults with ID who require AAC (Beukelman & Mirenda, 2013; World Health Organization [WHO], 2001).

From the perspective of the ICF, environmental factors that may affect functioning and participation in persons with disabilities can be found in the "physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001, p. 10). The WHO (2001) describe five overarching codes that should be considered when exploring factors

occurring within the individual's environment. These codes may exist as barriers or facilitators, i.e. aspects of the environment which have a negative or positive effect on disability respectively. Use of products and technology for personal use in daily life, an individual's physical environment, interpersonal support and relationships, attitudes of society and people living in society as well as services, systems and policies implemented in the individuals macrosystem make up these codes (WHO, 2001).

When the environmental factors of the ICF are interpreted from the perspective of the individual with communication difficulties, they are similar to "opportunity barriers" as mentioned in the Participation Model (Raghavendra, Bornman, Granlund, & Björck-Åkesson, 2007). Opportunity barriers present as factors which limit opportunities for participation for individuals requiring AAC and pertain to (1) legislative or regulatory policies, (2) common practises conducted by those working with individuals requiring AAC, (3) facilitator skills in implementing AAC, (4) facilitator knowledge of best practises in AAC and (5) attitudes and beliefs of those interacting with the individual requiring AAC (Beukelman & Mirenda, 2013).

In addition to opportunity barriers, access barriers which pertain to capability, attitudes and resource limitations experienced by individuals who require AAC may also interfere with communicative participation for adults with ID (Beukelman & Mirenda, 2013). For example, due to limited funding or adverse attitudes towards the use of AAC, the individual may not have access to necessary AAC systems or devices.

The ICF and Participation Model frameworks emphasize the dynamic interaction between the individual who requires AAC, the communication facilitator and the environment in which they undertake daily activities (Huer & Threats, 2016). Facilitator skill and knowledge of AAC interventions are emphasised in both, highlighting the importance of the facilitator needing to learn how to interpret the individual's form of communication and adjust their communication style to accommodate them. Furthermore, facilitators should be skilled in using communication partner interaction skills such as modelling, expectant time delay or asking open-ended questions to develop the communicative skills of the individual requiring AAC (Kent-walsh et al., 2015).

When considering the impact of environmental factors on communication support within residential facilities, literature states how adults with ID may experience significant

communication-related barriers. Dalton and Sweeney (2010) describe many of such factors identified from their study with a similar population. These barriers included; managerial structures failing to promote a positive approach to communication support, a lack of accessible services such as speech and language therapy and staff lacking the skills to facilitate communication effectively. Furthermore, staff training in specialist approaches to communication such as the use of assistive technology was not provided, inconsistent approaches to providing communication supports were carried out and lastly, a lack of comprehensive assessment of communication goals, interventions and achievements was identified.

1.4 Residential settings for adults with ID in the Western Cape

Many family members of adults with ID are unable to accommodate their needs in a home-based setting due to a variety of factors. High level of support needs, financial restrictions, employment commitments and/or lack of access to services may result in adults with ID requiring residential support (Yoong & Koritsas, 2012). Based on information from local ID forums, there are currently approximately 42 non-governmental, community-based residential facilities providing support to individuals with various levels of ID and needs in the Western Cape. These facilities identify as either a residential centre, group home or a combination of both.

Residential centres and group homes for adults with ID can be identified as live-in facilities where short- or long-term care and supervision is provided to residents as required. The understanding of what exactly a group home is, remains ambiguous in literature however they were created as a means of deinstitutionalizing individuals with disabilities such as ID, allowing them to gain social acceptance by becoming part of local communities while receiving necessary assistance or support from staff (Kozma, Mansell, & Beadle-Brown, 2009). They are generally understood to have a small number of residents who live together in a house (along with a house parent), sharing domestic responsibilities and participating in daily activities such as attending employment and doing grocery shopping.

Residential centres, on the other hand, typically exist within a larger organisation and have a larger number of residents who live in allocated housing (Kozma et al., 2009). Adults with ID living in residential centres often possess higher levels of support needs and

increased dependence on staff for assistance with self-care tasks and activities of daily living. In some instances, both a residential centre and group home exist within a facility, and the individual requiring residential support is placed according to their level of independence.

McKenzie et al. (2014) determined that at the time of their study, the majority of residential facilities for adults with ID in the Western Cape were residential centres as opposed to group homes. The smallest facility, a group home, housed only four residents while the largest, a residential centre, had up to 301 residents. Additionally, over 800 staff were employed by the 37 residential facilities they investigated in the Western Cape with more than half employed as care workers. A mean ratio of residents to care staff stood at 4.2:1. The managers of the facilities comprised of nurses, therapists, social workers, educators, administrative workers, as well as "self-taught" individuals. Funding was acquired from various sources such as government subsidies, disability grants paid by the residents, fees paid by the residents' families and charitable donations (McKenzie et al., 2014).

The funding acquired by the facilities is used to pay for goods and services required by the facility and adults with ID. That being said, services provided within many residential facilities in South Africa are often prioritised around providing basic care rather than enhancing the quality of life and promoting human rights (Capri et al., 2018). Human rights regarding healthcare, autonomy, employment and more specific to this study, communication are often overlooked. However, without private funding or charitable donations, specialised forms of therapy such as physiotherapy, occupational therapy and speech therapy that can offer support to facilities in these regards are often unavailable on-site (Dalton & Sweeney, 2013; Foskett, 2014).

Reichenberg (2013) states how recreational activities offered to adults with ID within this setting are often more pacifying and offer little intellectual challenges with most spare time spent waiting for mealtimes, physical exercise or to go to bed. Other activities such as engaging with literature or participating in vocational and social activities that offer intellectual stimulation, rich opportunities for communication and increased quality of life are often absent. Opportunities for literacy practices, for example, are typically limited due to misconceptions that adults with ID are incapable of developing literacy or the literary materials available are unsuitable for their age and/or support needs (Reichenberg, 2013).

After investigating residential facilities in the Western Cape, McKenzie et al. (2014) concluded that "major reconsideration" (p. 53) of service provision is necessary in order for South Africa to live up to its obligations to the UNCRPD as they are under-prioritised by government legislature and under-resourced. Based on reports from facility managers it was found that a significant challenge of residential facilities is a lack of service provision pertaining to mental health, challenging behaviour and medication (McKenzie et al., 2014). Finding from the current study could assist in identifying whether South Africa is in fact realising the communicative rights of adults with ID in residential facilities through necessary service and resource provision.

1.5 Supporting communication in adults with ID

Communication plays an integral part in our experience of the world and participation in daily life (Mcleod, 2018). Many adults with ID experience a range of difficulties in communicating due to impairments in hearing, understanding, speaking, pragmatics, reading and/or writing (Schalick, Westbrook, & Young, 2012). Sutherland et al. (2014) estimated that up to half of adults with ID require AAC to support their speech due to difficulty spontaneously communicating. Furthermore, McKenzie, Adnams and McConkey (2013) found that at the time of their study, sixty-two per cent of facilities for adults with ID in the Western Cape reported that most of their residents needed help in communicating with others.

The degree of communication difficulty experienced in these areas is usually associated with severity of ID with persons with more severe forms usually experiencing more significant challenges. For example, individuals with more severe forms of ID may be non-verbal, relying on informal methods of communication such as gesture or vocalisations while individuals with milder forms of ID may be capable of using spoken words to convey a message (Schalick et al., 2012).

Individuals with ID may also have particular communicative skills and difficulties as a result of a co-occurring condition. For example; those with Down Syndrome may have relative strengths in receptive language and vocabulary, but difficulty with speech intelligibility and limited expressive language complexity (Martin, Klusek, Estigarribia, & Roberts, 2009). Similarly, individuals with fragile X syndrome may have receptive language

strengths however their speech is often characterized by frequent perseveration of words and phrases (Schalick et al., 2012).

Due to a lack of or severely limited functional speech, many adults with ID can be described as having CCN. They may (1) have speech that is difficult to understand, (2) have difficulties in understanding what is being said, and/or (3) have challenges in expressing themselves due to limitations with vocabulary and sentence formulation (Iacono & Johnson, 2004). Due to such challenges, opportunities to express needs and wants, develop social relationships and exchange information with others are severely constrained (Light & McNaughton, 2015). Opportunities for personal autonomy through self-determination may also be limited as meaningful decisions with short- and long-term effects are often made without their involvement (O'Donovan, Byrne, McCallion, & McCarron, 2017).

Furthermore, literacy development proves an important skill for adults with ID requiring AAC for a variety of reasons as it; (1) provides access to language (2) enhances communication and self-expression (3) builds critical thinking (4) provides education and vocational opportunities (5) increases self-worth and independence and (6) allows individuals to access the world beyond their immediate environment (Light & McNaughton, 2009; Moni, Jobling, Morgan, & Lloyd, 2011).

The development of literacy is however a complex process influenced by both intrinsic and extrinsic factors experienced by the individual requiring AAC i.e. personal characteristics as well as environmental factors (Light & McNaughton, 2009). Intrinsic factors possibly experienced by adults with ID that may negatively impact the development of literacy include sensory and/or motor impairment, difficulties with phonological awareness skills, linguistic limitations affecting comprehension and production of text as well as memory and executive functioning limitations (Light & McNaughton, 2009). On the other hand, extrinsic factors such as limited access to materials, partner dominated interactions with literacy activities, low expectation of literacy attainment and a lack of prioritisation of literacy compared to other more immediate needs severely limit opportunities to develop literacy skills (Light & McNaughton, 2009).

Although some intrinsic and extrinsic factors may be out of the control of the individuals who support those requiring AAC, adaptions and support strategies can be implemented to account for the limitations that are more easily amendable (Light & McNaughton, 2009). For

example, reading or writing materials can be adapted to improve access for those with motor difficulties or alternative methods of responding such as pointing can be encouraged to increase participation in literacy activities. Implementation of such techniques can provide access to literacy learning and consequently impact autonomy, leisure as well as education. For example, individuals may experience a lack of self-determination in daily activities requiring literacy skills such as reading or completing administrative forms. Furthermore, reading and writing for leisure can improve quality of life and promote social interactions around literary experiences (Moni et al., 2011).

Acquiring functional communication can improve meaningful interpersonal interactions for adults with ID and consequently improve overall participation within their immediate environment, positively impacting their quality of life (Light & McNaughton, 2015). Feelings of loneliness, which are commonly experienced by individuals with ID due to communication difficulties, limited socialisation and a lack of self-determination, are often reduced when provided with an effective communication system (Stancliffe et al., 2010). Furthermore, a means of functional communication can lessen vulnerability in adults with ID by providing a way to report crime or abuse to authorities especially when considering that approximately 45% of adults with CCN have been victims of crime and abuse (Bornman et al., 2011; Light & McNaughton, 2015).

The inability for individuals with ID to adequately communicate their needs, wants and preferences may also result in frustration causing challenging behaviour (Hutchins & Prelock, 2014). Challenging behaviour such as self-injury, physical aggression or destructive and disruptive behaviour is a frequent concern for those caring for individuals with ID. Interpreting such behaviours as communicative or providing an alternative means of communication can assist in reducing these behaviours and inhibit the exclusion of these individuals from education- or community-based services, which are essential opportunities for learning and personal development (Hutchins & Prelock, 2014).

Additionally, providing an effective means of communication to adults with ID and CCN can potentially lead to improved physical and mental health outcomes. Communicating their symptoms to people within their environments such as family members or staff at residential facilities allows for earlier identification of health-related concerns (Njenga, 2009). Effective communication further promotes person-centred care for adults with ID who are consulting

healthcare professionals by creating opportunities for participation in decision-making pertaining to healthcare assessments and interventions (Ratti, 2018).

Various types of communication supports can be implemented with adults with ID in residential facilities namely, (1) clinical therapeutic services such as speech-language therapy or occupational therapy, (2) environmental modifications, (3) assistive technology, and (4) strategies and techniques employed by potential communication partners at the facility (Dalton and Sweeney, 2010). AAC provides a means of supporting communication in residential facilities for adults with ID as it consists of a range of strategies, techniques and tools used to supplement or replace natural speech for those with impairments in language comprehension and production (Beukelman & Mirenda, 2013). For example; a speech therapist may introduce AAC tools or techniques to the adults during therapy and/or visual schedules may be utilised by staff as an environmental modification to augment comprehension of language.

AAC strategies can be unaided, where the individual uses only their body to communicate (such as using gestures or manual signing) or aided which involves the use of external equipment to enable the individual to communicate (Van der Meer, Sigafoos, O'Reilly & Lancioni, 2011). Furthermore, aided AAC systems can range from low-technology (such as using pen and paper or a communication board to convey a message), to light-technology (such as a speech-generating device with limited message options and voice recording functionality) to high-technology systems (such as a computing device with a dynamic display and text-to-speech output) (Van der Meer et al., 2011).

A range of symbols can be used on aided AAC systems to represent messages, concepts and words. Aided AAC systems may include object symbols (objects, miniature objects or parts of objects), single meaning pictures (one picture is used to represent a word or phrase), semantic compaction (pictures take on multiple meanings and are used in sequence to create words or phrases), or alphabet-based methods (spelling, word prediction or whole word selection) (Hill, 2010).

Based on the individual's understanding of symbols an appropriate language representation method (or a combination thereof) is selected. The development of literacy can open up a range of communicative possibilities for individuals using AAC as alphabet-based methods prove the most flexible. Users can generate novel messages as opposed to being

limited to the non-orthographic symbols available in the AAC system (Millar, Light, & McNaughton, 2004). Determining the adult's skills, challenges and needs pertaining to communication and the use of AAC is therefore essential.

According to Von Tetzchner and Martinsen (2000), there are three different groups of individuals who may benefit from AAC, namely the expressive language group, supportive language group and alternative language group. Firstly, the expressive language group consists of individuals who have adequate receptive language skills; however they have difficulty expressing themselves. Secondly, the supportive language group is comprised of two subgroups that include individuals who temporarily use AAC to facilitate language comprehension and expression as well as individuals who speak but have difficulty being understood. Thirdly, the alternative language group requires AAC as a permanent means of receptive and expressive communication. This indicates the variation of AAC interventions that may be required for the adults within residential facilities.

The implementation of AAC systems and strategies requires strategies and procedures to teach their use along with multiple opportunities to practice using them in meaningful situations. Knowledgeable and skilled facilitators are thus required to model, implement and maintain the use of AAC systems and strategies (Kent-Walsh & McNaughton, 2005). In residential facilities for adults with ID, care staff play an important role in day-to-day AAC facilitation as they frequently communicate with the adults with ID (Dalton & Sweeney, 2010).

As effective communication facilitators, staff should be knowledgeable about the individual's method of communicating and utilise strategies to guide successful communicative exchanges. Such strategies may include acknowledging all communication attempts, creating opportunities for communication, adapting ways of speaking and facilitating the use of AAC methods (Mitchell, 2009). However, due to frequent staff changes or staff working different shifts, it may prove challenging to provide consistent communication support to the adults as well as sustainable training for the staff (Iacono & Johnson, 2004).

Sutherland et al. (2014, p. 120) describe how facilitator skill and knowledge are particularly lacking within residential facilities in New Zealand for adults with ID as they identified a "client need/staff skill discrepancy" where 28.8% of adults required AAC

however less than 25% of staff had any insight into AAC. Finding from Siu et al. (2010) agree as they state how facilities for adults with ID in Hong Kong reported a poor understanding of AAC with fewer instances of AAC intervention identified as opposed to services available for children with CCN.

It was surmised by Sutherland et al. (2014) that, along with a lack of experience, information and training related to AAC, a lack of input from specialist services in the field of AAC, such as a speech-language therapist, could account for the need/skill discrepancy. Input through the transference of relevant knowledge and skill is required from an individual experienced in the field of AAC in order for care staff to become successful communication facilitators. Without access to speech and language therapy services and training, it proves challenging for the care staff to determine the need for AAC, implement a communication system and train all potential communication partners on its use. Moreover, communication is better supported in environments where a multidisciplinary team approach is adopted, and therapeutic efforts are integrated into the environment (Dalton & Sweeney, 2010).

On the other hand, factors that facilitate communication within residential facilities were also identified by Dalton and Sweeney (2010). Those most relevant to the current study state that first, a positive service philosophy regarding communication that promotes human rights, quality of life, inclusion and participation is important; second, expectations should be maintained by staff that all adults can and do communicate in some way; third, the role of staff as communication partners in the adults social network should be recognised; fourth, regular assessments of the communicative skills of both the adults and staff should be completed; fifth, individualised communication goals should be identified for each adult; and, last, care staff should use every opportunity and method of communication with service users and adapt methods and environments accordingly.

1.6 Summary

Adults with ID experience a range of communication skills and challenges due to varied impairment in intellectual and adaptive functioning. This affects their ability to communicate their needs, wants and preferences, consequently impacting their quality of life. Staff working in residential facilities play an important role in supporting and interpreting the adult's communication as they present as frequent communication partners. A variety of AAC strategies and systems can be implemented by staff to support communication. Although

service delivery for persons with ID in South Africa has drastically improved since the late twentieth century, residential facilities for adults with ID in the Western Cape remain under-prioritised and under-resourced by government. Therefore, staff working within these facilities may not have access to necessary resources to support communication effectively.

2. METHODOLOGY

2.1 Aims

2.1.1 Main aim

The main aim of the study was to describe the communication skills, resources and needs of adults with intellectual disability living in residential facilities in the Western Cape and their support staff, as reported by facility managers.

2.1.2 Sub-aims

In order to address the main aim, four sub-aims were formulated. The sub-aims of the study were:

i. To describe the communication and related skills of adults with intellectual disability living in residential facilities;
ii. To describe the communication skills and strategies used by staff who communicate with adults who have communication difficulties;
iii. To describe current communication resources and support services available to the staff and adults with intellectual disability;
iv. To describe the needs of the staff and adults with intellectual disability pertaining to communication resources and support services.

2.2 Research design and phases

A quantitative, non-experimental survey design was utilised for this study. Additionally, the data obtained from open-ended questions and opportunities to comment in the survey was analysed qualitatively by means of an inductive thematic analysis. A survey research design is often employed in research to describe and measure phenomena without direct manipulation by the researcher, allowing for an accurate representation of occurrences within a population (McMillan & Schumacher, 2014). Additionally, accurate information can be obtained from large groups of participants efficiently and cost-effectively using this method (McMillan & Schumacher, 2014).

The limitations of a survey design include a reduced response rate. To alleviate this limitation, potential influencers on response rates were identified and considered namely survey length, telephonic pre-notification and follow up contact (Bartel Sheehan, 2001).

The phases of the study are depicted in Figure 1.

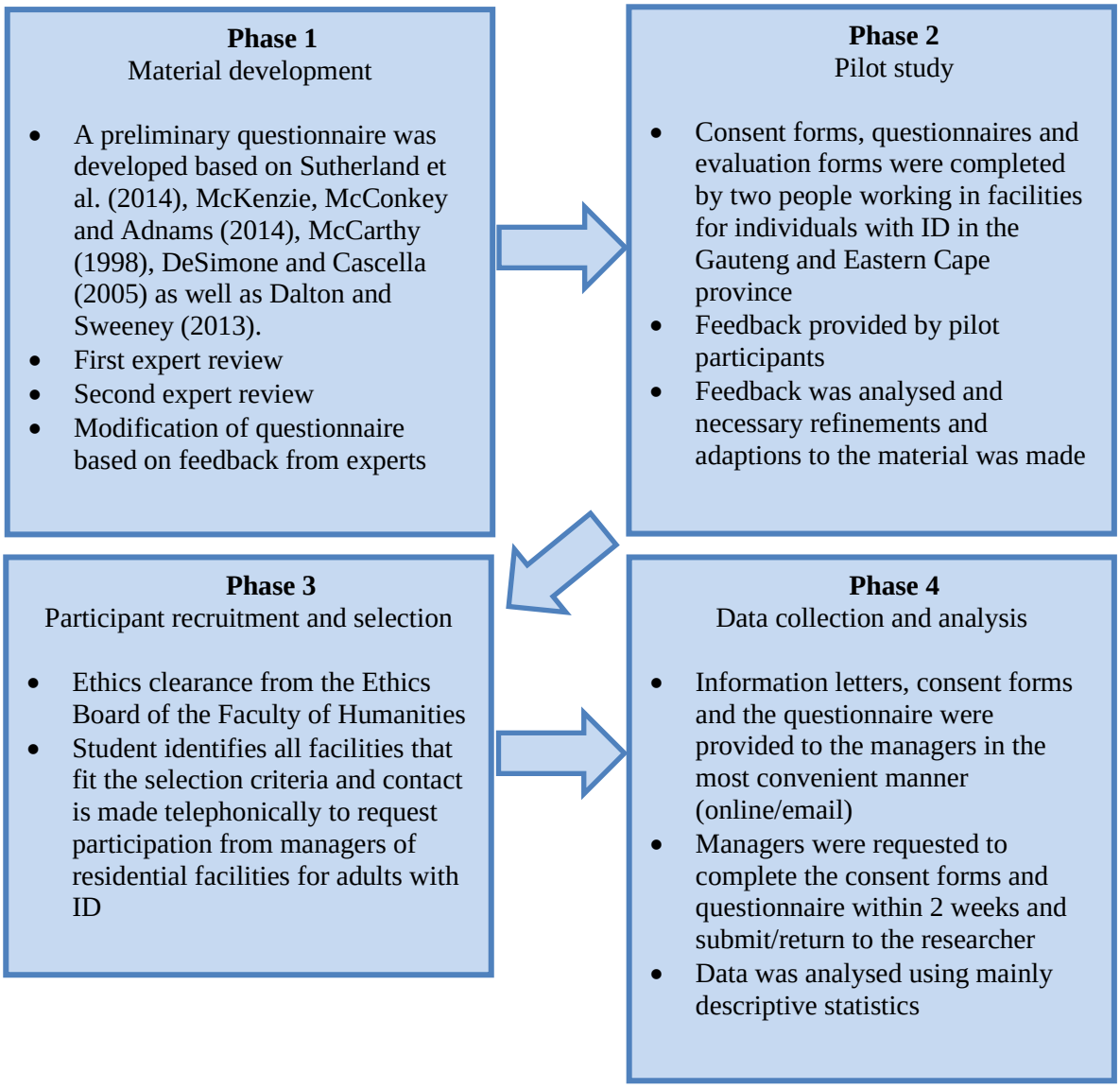


Figure 1. *Phases of the study.*

2.3 Participants

2.3.1 Description of the context

Participants were obtained from the Western Cape as convenience sampling was employed whereby the data sources most accessible to the researcher were invited to participate in the study (McMillan & Schumacher, 2014). The Western Cape is one of nine provinces in South Africa, situated on the south-western coast of the country. Approximately 11.3% of the national population or 6.3 million people live in the Western Cape on 129 370km² of land. The Western Cape can be divided into six districts namely; Cape Winelands, Central Karoo, City of Cape Town, Garden Route, Overberg and West Coast. Figure 2 provides an overview of the location of these districts. According to Statistics South Africa (Stats SA, 2013), approximately 60% of the population lives in the Cape Town metropolitan area while 40% live in small towns or rural settlements.

The Western Cape is one of the wealthiest provinces in South Africa with the lowest provincial unemployment rate (13.1%) as well as the lowest rural unemployment rate (15.7%) (Stats SA, 2013). That being said, the unemployment rate in the Western Cape does appear exceedingly high in comparison to middle- and high-income countries such as the United States of America and the United Kingdom who have a 3.7% and 3.8% unemployment rate respectively (Bureau of Labor Statistics, 2019; Eurostat, 2019). Afrikaans, isiXhosa and English are recognized as the official provincial languages with Afrikaans being spoken predominantly as a home language (49.7%) followed by isiXhosa (24.72%) and English (20.25%) (Stats SA, 2013).

Furthermore, 5.4% of persons aged five years and older in the Western Cape are living with a disability, lower than the national disability prevalence rate of 7.5%. Impairment based self-report questions used to gather disability statistics identified that most individuals with disabilities in South Africa reported having seeing difficulties (11%), followed by remembering/concentrating difficulties (4.2%), hearing difficulties (3.6), walking difficulties (3.5%), self-care difficulties (3.4%) and communication difficulties (1.5%) (Stats SA, 2013). That being said, the self-report questions used to gather disability statistics were limited in nature as they did not specifically question the prevalence of ID, rather identifying the difficulties that individuals faced. Since individuals with ID often have difficulties in multiple

areas mentioned above as well as many additional, their disability may be incorrectly reported or inaccurately interpreted by Statistics South Africa, possibly affecting the provision of necessary services by government structures.

When considering specific districts within the Western Cape, the Central Karoo had the highest proportion of individuals with disabilities with 8.1% of the population reporting impairment while the City of Cape Town had the lowest proportion with 5% (Stats SA, 2013). Districts in predominantly remote or rural areas such as Central Karoo, Garden Route and West Coast have been identified as having a higher prevalence of disability (a mean of 7.1%), most likely due to reduced access to health care services to prevent or cure illnesses which cause disability (Vergunst et al., 2017).

Furthermore, a high incidence of FASD (55 out of 1000 babies born in Western Cape) and prevalence of drug-related violence in rural areas may also account for more people living with disabilities in these areas (Olivier, Curfs, & Viljoen, 2016). The higher incidence of FASD and occurrence of head injuries related to violence could thus signify a higher prevalence of ID in the rural Western Cape districts as opposed to central lying districts.

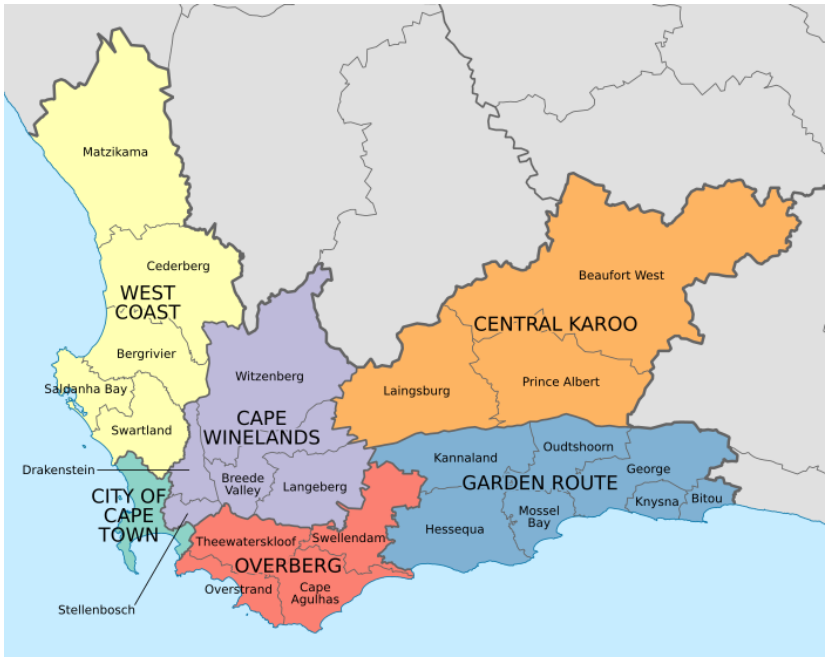


Figure 2. *Map of the districts of the Western Cape.*

2.3.2 Selection Criteria

The selection criteria that the participants were required to meet are presented in Table 1 below.

Table 1

Participant Selection Criteria

Criterion	**Justification**	**Measure used**
Manager at a residential facility for adults with ID or staff member appointed by the manager of the residential facility to complete the questionnaire	The participant needed to be in contact with the required setting and population and be knowledgeable of the residents. Due to time constraints and the fact that facility managers may not have had detailed knowledge of the resident's skills, they could delegate the completion of the questionnaire to a member of staff in the facility if required.	During recruitment, it was clarified that the focus will be on this population. It was stated during initial telephonic contact that managers could delegate the task to another member of staff who is knowledgeable of the residents.
Good English literacy skills	An English written questionnaire was used as the data collection instrument	Confirmed through self-report during initial telephonic contact. Managers were required to comment on the English skills of the appointed staff member if they had delegated the task.

Criteria were also set as to the type of residential facility that managers were working at. These criteria are set out in Table 2.

Table 2

Facility Selection Criteria

Criterion	**Justification**	**Measure used**
Facility for adults (individuals older than 18) with ID	This is the population that was focused on for this study. Facilities were being excluded if they catered only for the aged (without ID),	Identified on Western Cape Forum for Intellectual Disability and Department of Social Development websites or through a Google search

Criterion	Justification	Measure used
	only for persons with other types of disability or only for children with ID. Facilities for adults with disabilities that included adults with and without ID were included. However questions asked in the questionnaires pertained only to residents with ID.	
Non-governmental	State hospitals with residential accommodation are currently being phased out and are therefore of less relevance for this study	Identified on Western Cape Forum for Intellectual Disability and Department of Social Development websites or through a Google search

2.3.3 Recruitment

Clearance from the ethics committee of the Faculty of Humanities, University of Pretoria (Appendix A) was obtained before recruitment commenced. As these facilities were non-governmental, permission from a governmental department was not required. Since the participants were selected based on required characteristics for the study, purposeful and comprehensive sampling was utilised (McMillan & Schumacher, 2014).

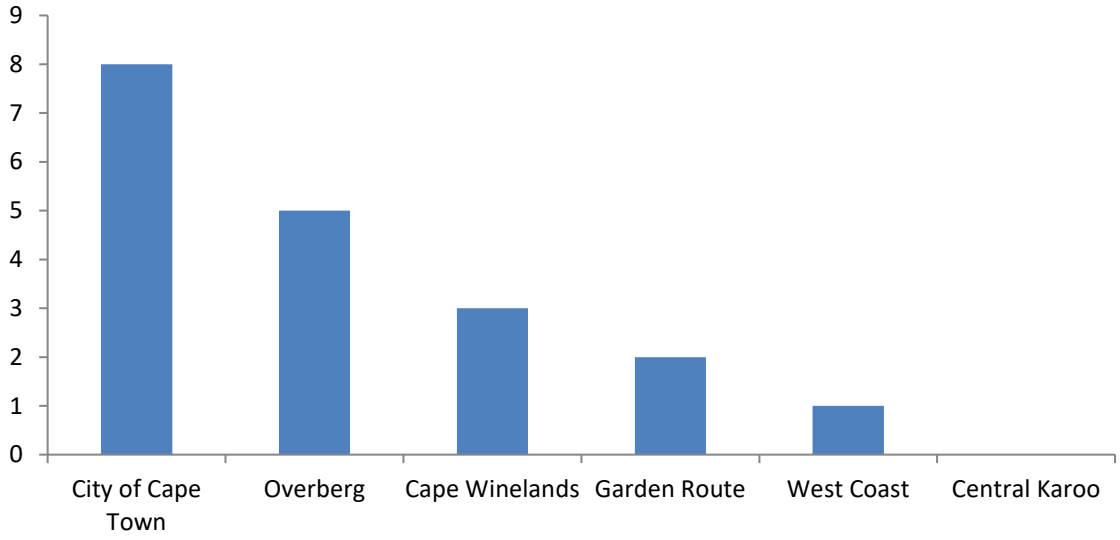
Residential facilities serving adults with ID were identified from existing databases maintained by the Western Cape Forum for Intellectual Disability (WCFID) and the Western Cape Government's Department of Social Development (DSD). A Google search was also employed to identify any facilities that may have been omitted from the databases. Such facilities included residential centres, group homes, and facilities that included both types of living arrangements.

A total of 42 facilities that appeared to fit the facility selection criteria were identified and approached for participation. Five facilities that were initially thought to be appropriate did not fit the criteria once contact was made, and more information about the residents or services was obtained. Furthermore, one facility declined to participate, and 17 facilities were either uncontactable or unresponsive when attempting to engage with relevant individuals. A total of 19 facilities agreed to participate.

2.3.4 Participant and facility description

The facilities from which the participants were recruited were located across the Western Cape in both urban and rural areas. No facilities were however recruited from the Central Karoo, with recruitment being affected by the reduced number of facilities in this district when compared to other districts. Figure 3 stipulates the number of facilities that participated in each district.

Figure 3. *Number of participating facilities in each district of the Western Cape.*



A description of each facility concerning location, type, number of adults with ID and number of staff is indicated in Table 3. The ratio of staff to adults ranged from 1:1.5 to 1:5.5. When considering types of facilities within the organisations, participants specified whether the facility at which they were employed or which they owned was a residential centre, a group home or a mixed residential centre and group home. If it was a different type of facility, a description was required. Out of 19 facilities, nine identified as a residential centre, eight as a group home, one as a mixed residential centre and group home and one which was described as an assisted living facility with enrichment programme for adults with Autism. Furthermore, one facility which identified as a residential facility also stated that they provide social community services to people with epilepsy living in the surrounding areas.

The number of adults and staff in each facility is given in Table 3. The number of adults with ID ranged from four to 220 while the number of staff ranged from two to 49. A description of the participants pertaining to gender and position is also provided in Table 3

below. In summary, 17 participants were female, while two were male. Many participants (n = 6) stated their position in the organisation as a house parent (including house mothers or house leaders), while many others (*n* = 6) identified as a manager (including executive managers and project managers). The remaining participants held a variety of titles such as an administrator, head of therapeutic services or chairman of the board.

Table 3

Description of the Participants, Facilities, Adults and Staff

Participant ID	Gender	Position in organisation	Type of facility	District	Number of adults with ID	Number of staff	Staff to adult ratio
1	Female	Administrator	Residential centre	City of CT	47	15	1:3.1
2	Female	Head of Therapeutic Services	Residential centre	Cape Winelands	135	31	1:4.4
3	Female	Manager	Residential centre	Garden Route	110	20	1:5.5
4	Female	Manager	Group home	City of CT	6	3	1:2
5	Female	Manager	Residential centre	City of CT	40	9	1:4.4
6	Female	House parent	Group home	City of CT	26	8	1:3.3
7	Female	Chief care officer	Residential centre	Cape Winelands	83	31	1:2.7
8	Male	Owner	Group home	West Coast	49	20	1:2.5
9	Female	Housemother	Mixed residential and group home	Overberg	20	13	1:1.5
10	Female	Founder and development manager	Residential centre	City of CT	4	2	1:2
11	Female	Executive Manager	Residential centre	Cape Winelands	111	35	1:3.2

Participant ID	Gender	Position in organisation	Type of facility	District	Number of adults with ID	Number of staff	Staff to adult ratio
12	Male	Chairman of the board	Group home	City of CT	7	2	1:3.5
13	Female	Manager	Residential centre	City of CT	220	49	1:4.5
14	Female	Project manager	Other (Assisted living)	City of CT	8	6	1:1.3
15	Female	Branch director	Residential centre	Garden Route	52	15	1:3.5
16 [a]	Female	House leader	Group home	Overberg	7	19	1:2.7
17 [a]	Female	House leader	Group home	Overberg	10	18	1:1.8
18 [a]	Female	House leader	Group home	Overberg	7	19	1:2.7
19 [a]	Female	House leader	Group home	Overberg	7	19	1:2.7

[a] *Participants #16 through to #19 were from the same organisation; however, they managed their respective facility mostly independently and thus completed four separate questionnaires.*

2.4 Materials and equipment

The materials used in this study comprised of information letters, consent forms as well as a self-administered questionnaire. The questionnaire was also available in an online survey format using Qualtrics software.

2.4.1 Information letters and consent forms

An information letter and consent form in English (Appendix B) was sent to potential participants. The information letter stated the purpose of the study and the rationale for it, intended participants, participants' rights, and the plan for data management and dissemination of results. A consent form was included where facility managers could accept or decline to participate in the study.

2.4.2 Self-administered questionnaire

The self-administered questionnaire (Appendix C) was based on existing questionnaires by McCarthy (1998), DeSimone and Cascella (2005), McKenzie et al. (2014), Dalton and Sweeney (2013) as well as Sutherland et al. (2014). The existing questionnaires were identified through literature searches containing keywords pertaining to certain aspects of the questionnaire such as "residential facilities", "adults with intellectual disability", "communication support", "communication needs" and "communication partner". Contributions from each of these questionnaires were used to ensure that the question items included would provide a comprehensive description of the population and context at hand, as well as gather appropriate information about the communication and related skills of adults with ID as well as the staff interacting with them.

The questionnaire by McKenzie et al. (2014) looked into living arrangements for people with ID in the Western Cape. This questionnaire provided insight for Section A of the current questionnaire, which aimed to gather background information. Question items regarding the participants and facility were investigated in particular. Additionally, since the same participants were used in the current study (facility managers in the Western Cape), the vocabulary and level of language were noted as to inform the wording of the question items.

The questionnaire by Sutherland et al. (2014) looked into communication intervention for adults with ID receiving services in New Zealand agencies. This questionnaire informed Section A, B and D of the current questionnaire particularly regarding the residents' communicative skills and AAC needs as well as staff interaction with AAC.

Lastly, the questionnaire by McCarthy (1998) entitled *Communication Supports Checklist (CSC) for Programs Serving Individuals with Severe Disabilities* further adapted by DeSimone and Cascella (2005) as well as Dalton and Sweeney (2013) was used to inform Section C and D of the current questionnaire. Two categories of the CSC, as mentioned by Dalton and Sweeney (2013) were identified as relevant to the current study and were used to inform question items namely; (1) overall organisation supports for communication including attitudes towards communication support and environmental tools and strategies to support communication; and (2) team competencies including staff or team knowledge, skills and experience. A preliminary questionnaire was created based on these sources.

The preliminary questionnaire was adapted to the population and context targeted in this study based on:

a. Initial expert review by one academic
b. Subsequent expert reviews by two speech-language therapists working directly with adults with intellectual disability
c. Results from the pilot study (as reported in Section 2.5).

The preliminary questionnaire was reviewed by a qualified speech-language therapist who is a Professor in Disability Studies with special expertise in adults with ID and experience in survey research about this population. The review was conducted as part of the review of the research proposal for the current study. Changes were made after the review included shortening the questionnaire as the length was deemed a concern. Question items concerning the participant's age, qualifications and experience were removed from Section A as they were identified to be not directly relevant to the aims of the study.

The subsequent expert reviewers were two speech-language therapists with two and four years of experience respectively in providing communication interventions with adults with ID, one in public and the other in the private health sector.

These expert reviewers were each provided with the preliminary questionnaire as well as a feedback form (see Appendix D). They were asked to:

1. indicate if anything additional was needed on an item,
2. indicate if any items should be excluded as they are not appropriate,
3. specify if any items were unclear,
4. suggest changes to items in order for all items to be appropriate to the context and participants, and
5. comment in general on the length and formatting of the questionnaire.

After the subsequent expert reviews, it was indicated that length was still a concern. Question items in Section A were combined to further reduce the question items and sustain relevance to the aims. Furthermore, one of the expert reviewers had previously undertaken survey research with a similar population and reported that late submissions and delayed or no responses were a challenge. Late or delayed responses were thus anticipated, and strategies such as initial telephonic contact and telephonic reminders were conducted. Lastly, it was suggested that certain questions should be reworded or examples should be provided to ensure they would be fully understood by the participants and reduce the need for following up on responses.

The revisions made to the questionnaire following the pilot study are detailed in Table 4.

2.4.3 Qualtrics online survey software

Qualtrics software is a web-based survey tool used by researchers across a variety of academic fields to create and distribute surveys as well as analyse responses (Snow & Mann, 2013). Participants are provided a web link via email which allows them access to the online survey. Due to its ease of use, completion of an online survey using Qualtrics software proves particularly efficient for both the researcher and participant. However, limitations in internet connectivity and technological skills may present as factors leading to the utilisation of alternative methods.

2.5 Pilot study

A pilot study was conducted to ensure that the materials and procedures intended for the main study were appropriate.

2.5.1 Participants

The pilot study was conducted with two participants. Both participants complied with all selection criteria, as seen in Table 1 and Table 2. Since comprehensive sampling was utilized for the main study, residential facilities within alternative provinces of South Africa were called upon for the pilot study. The first participant was the manager of a day care, residence and vocational stimulation centre for adults with Autism in Gauteng. The second participant was the manager of a residential and vocational centre for adults with ID in the Eastern Cape. The questionnaire was made available to the pilot participants in different formats namely a word and PDF document that could be completed electronically or manually and returned via email or fax as well as an online survey using Qualtrics online survey software.

2.5.2 Aims, materials, procedures, results and recommendations

Table 4 gives an overview of the aims of the pilot study, the materials and procedures utilised, the results and the subsequent recommendations.

Table 4

Pilot Study Aims, Materials, Procedures, Results and Recommendations

Aim	Material	Procedures	Results	Changes for main study
To determine whether managers of residential facilities have the required knowledge to be able to complete the questionnaire appropriately.	Questionnaire (Appendix C) and questionnaire evaluation form (Appendix D)	The participant completed an evaluation form after completing the questionnaire, commenting on the extent to which he/she found it easy to answer the questions.	Participants were able to answer the questionnaire appropriately and found the ease of completion satisfactory.	No changes needed
To evaluate the clarity of the instructions provided regarding the completion of the questionnaire.	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, reviewing the clarity of the instructions provided.	Participants completed the questionnaire as required and did not raise any concerns regarding the clarity of the instructions provided.	No changes needed
To evaluate the clarity and relevance of the items in the questionnaire.	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, reviewing the clarity and relevance of the items in the questionnaire.	Participants stated that an additional response option should be added to Q3 to differentiate between home carers, nursing assistants, staff /enrolled nurses and registered nurses as there is a vast difference between their scopes of practise and subsequent responsibilities.	Q3 was revised to include home carer, nursing assistant, staff nurse and registered nurse response options. The following question regarding the highest level of education was removed due to redundancy as qualifications can be assumed based on job titles.
			Participants stated that in Q8, it was unclear whether an adult still had a hearing loss or visual impairment if they made use of an assistive device which corrected the impairment.	Q8 was revised to include those with and without assistive devices such as spectacles, hearing aids or wheelchairs.
			Participants suggested that FASD be added to Q8.	FASD was added as a response option to Q8.

			Participants suggested that "and/or" be added to the example in Q19 as more than one of the statements listed may be true.	"and/or" was included between the two statements in the example in Q19.
To ensure the questionnaire items (and their examples) were contextually and culturally appropriate.	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, reviewing the contextual and cultural appropriateness of the items.	Participants deemed the questionnaire culturally appropriate.	No changes needed
To ensure that the layout of the questionnaire is visually pleasing.	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, reviewing the visual layout of the questionnaire.	Participants reported that the questionnaire was well set out and user-friendly.	No changes needed
To determine whether the questionnaire could be completed within the suggested time frame.	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, commenting on the time it took them to complete the questionnaire.	Participants were provided with two weeks in which to complete the questionnaire. Participants reported that the length of the questionnaire was satisfactory; however, it was suggested that the estimated time it would take to complete the questionnaire be clearly communicated to the main study participants during the initial contact.	A completion time of two weeks was deemed appropriate. No changes recommended regarding the questionnaire. The estimated amount of time required to complete the questionnaire was clearly stipulated during initial telephonic contact in the main study.
To evaluate the return rate and frequency of reminders needed for participants to return the questionnaire.	None	The researcher noted the return rate and frequency with which participants needed reminding to return the questionnaire.	Both participants returned all relevant materials. A reminder was sent to both participants after one week of distribution. One participant returned the questionnaire within the allocated time (two weeks). The	A reminder was sent after one week and participants were contacted telephonically when the questionnaire was not returned after the allocated two weeks.

			other participant returned the questionnaire one week past the due date.	
To evaluate the completeness of the returned questionnaires	None	The researcher noted the completeness of the questionnaires returned by the participants	One of the participants omitted information on two of the question items; they were contacted via email and asked to provide the required information.	The same procedures were followed in the main study when questionnaires were returned that had missing information.
To determine the appropriateness of the data collection techniques (email, online survey and fax)	Questionnaire and questionnaire evaluation form	The participant completed an evaluation form after completing the questionnaire, reviewing the appropriateness of the data collection techniques.	Emails were the preferred method for receiving and returning the materials. Neither participant chose the online survey format. Participants reported that the data collection techniques were satisfactory as they were well set out, easy to use and familiar to them.	No changes needed
To evaluate whether the intended data capturing process was effective	Excel sheet for data capturing	The researcher captured the data on an Excel sheet and a research assistant checked the accuracy of data entries.	The data capturing process was effective	No changes needed
To test coding procedures for open-ended questions	Completed questionnaires	The researcher coded the data and the appropriateness of the codes were evaluated along with the research supervisor	The codes were appropriate and effective to use	No changes needed
To evaluate whether the data collected will enable the answering of the research question.	Raw data	The researcher linked the data received with the aims and sub-aims of the study.	Descriptive statistics were decided upon for the main study supplemented by thematic analysis of qualitative data	No changes needed

2.6 Procedures

2.6.1 Data collection

Facility managers were contacted telephonically, briefly informed about the aims and methods of the study and asked if they would be interested in receiving more information. If they agreed, an information letter and consent form (Appendix B), along with the questionnaire (Appendix C) was provided to them via an online link, email or fax. The information was provided in English. If they wished to take part in the study, the participant was required to complete the consent form and return it to the researcher. The participants were requested to complete and return the questionnaire within two weeks. The participants were asked to provide their contact details at the end of the questionnaire to allow for follow up on some of the answers that were unclear with regards to legibility or word meaning.

Most participants (n = 14) completed the questionnaire by filling out the word document manually or electronically and returning it via email. Five participants made use of the online survey. No participants opted to receive and return the materials via fax.

Of the 19 participants, seven required telephonic or email reminders to return the questionnaire as they did not return it within the allocated time frame. Furthermore, almost all questionnaires (n = 18) were returned with one or more question items only being partially completed or not completed at all. Most often, participants misread the instructions, ticking the relevant box rather than providing an estimated number as required. Alternatively, pages or question items were overlooked and not completed, or a description was not provided although the participant indicated ‘yes’ to receiving or providing a particular resource or service. In such cases, the participant was contacted again to request that the omitted information be provided telephonically or included in the questionnaire and resent.

2.6.2 Data analysis

The data from the questionnaires was entered into an Excel spreadsheet in preparation for statistical analysis. Where appropriate, numerical codes were assigned to capture the data.

The numerical data was analysed quantitatively using the mathematical functions of Microsoft Excel®. Data was organised and summarised by means of descriptive statistics. Ratio and interval data was analysed by measures of central tendency and measures of variation, namely; mean, standard deviation and range (McMillan & Schumacher, 2014). Categorical data was analysed quantitatively by tallying the number of responses in each category. Data was presented using bar graphs and tables (McMillan & Schumacher, 2014).

Inductive thematic analysis was used to analyse the responses to open-ended questions and 'comment' options provided as additions to some of the closed-ended questions. According to Maguire and Delahunt (2017), thematic analysis proves useful in identifying patterns of interest in the data as well as interpreting and making sense of it. The analysis was inductive in that there was no pre-determined framework; themes were derived from the data that was collected (Braun & Clarke, 2006).

The six-phase framework for conducting a thematic analysis developed by Braun and Clarke (2006) was utilised in this process. First, the researcher became familiar with the data by reading and re-reading the transcripts. Second, initial codes were generated using line-by-line coding, supporting an inductive thematic analysis. Thirdly, the codes were examined and those that fitted together well were collated into a theme. Fourth, the themes were reviewed, in that the coherence and distinction between the themes were analysed. Those that were deemed incoherent or redundant were changed or removed. Fifth, the themes were defined and a thematic map was developed to determine what each theme is about and how they relate to each other. Sixth, the results of the thematic analysis were reported on in the results section of this paper.

2.6.3 Reliability and validity

Steps were taken to enhance the validity and reliability of the study. Since a novel instrument was developed, content validity was enhanced by basing it on existing questionnaires and literature to ensure the instrument is measuring the targeted construct (McMillan & Schumacher, 2014). Face validity, which concerns the judgement that items in an instrument appear to be relevant to the study, was established through expert review (McMillan & Schumacher, 2014). The pilot study also served to enhance the overall validity of the measuring instrument.

The reliability with which the raw data is transferred onto Microsoft Excel® was determined by having an independent person view 20% of the questionnaires and also capture the data onto a spreadsheet. The way the data was captured by this person was compared to the way the data was originally captured by the researcher. Percentage agreement in the way the data was captured was calculated using the following formula:

$$\frac{\text{Agreements}}{\text{agreements + disagreements}} \text{ x100}$$

The reliability of data entries was found to be 92%. Discrepancies were checked against the original questionnaires and corrected. Furthermore, in order to ensure the trustworthiness of the thematic coding employed, the development of codes was conducted in collaboration with the supervisor (Maguire & Delahunt, 2017).

2.7 Ethical issues

According to the World Medical Association Declaration of Helsinki (2013), when conducting research with human participants, it is important to promote respect as well as protect health and rights. The following ethical principles, as stipulated by the Belmont Report (1978), were upheld when conducting this study:

Autonomy was upheld by providing participants with the choice to participate in the study. It was made clear in the information letter that participation is voluntary, and no one will be forced or coerced to participate. Participants were informed that they could terminate their participation at any time with no penalty and should they wish to withdraw, their data would be destroyed immediately.

The participant was informed of the purpose, and all details of the study both telephonically and through the information letter before voluntary consent were obtained. Since the study consisted of observational reports from participants, there was no direct risk of physical or psychological harm. Although taking part in the study did not directly benefit the participants, the data collected and subsequent results may benefit AAC service provision in residential facilities in the Western Cape. Since the facilities that participated did not receive benefit compared to those who did not, justice will be upheld.

The privacy of the participants was protected by keeping all personal data confidential as well as appropriately storing de-identified data. Confidentiality was ensured by not disclosing the identities of the participants to any third parties. Any names (of the participant or facility) mentioned on the questionnaire were censored or replaced with a code. Only the researcher and the supervisor had access to any identifying information. Both paper copies and electronic forms of data were stored appropriately to protect the privacy of the participants. Any identifying information was censored prior to storage. Electronic data was placed onto a USB stick and along with the paper copies, stored after completion by the University of Pretoria, Centre for AAC for a minimum of 15 years.

3. RESULTS

This section will present the results of the questionnaire. The response rate will be presented first. This will be followed by the results pertaining to each of the sub-aims. A description will be given of the number and characteristics of the adults with ID that received services from the responding institutions, with specific focus on the communication skills of these individuals. This will be followed by a description of staff who worked directly with the adults with ID and the communication skills and strategies used by staff who communicate with adults who have communication difficulties. Thereafter, the current communication resources and support services available to the staff and adults will be presented, and finally, the needs of the staff and adults with ID pertaining to communication resources and support services. This section will end with a brief description of the themes that were identified in the qualitative responses provided by the participants.

3.1 Response rate

Nineteen out of 37 facilities that fit the selection criteria returned a completed questionnaire (response rate = 51%). This response rate was comparable to that of Sutherland et al., (2014) (57%) who also conducted survey research in residential facilities for adults with ID. On the other hand, McKenzie et al. (2014) had a much larger response rate (97%) than the present study. These researchers administered questionnaires in face-to-face interviews, which was not possible in the present study due to time and resource limitations. The following results are based on the 19 questionnaires received.

3.2 The communication and related skills of adults with ID

3.2.1 Number and characteristics of adults with ID

Participants were asked to provide an estimated number of adults with ID that receive support from their facility along with the age ranges of these individuals, their severity of ID and presence of any coexisting conditions. Of the 19 facilities, 10 (52.6%) offered services to not only adults with ID who resided at the facility (*n* = 794), but also to adults with ID who were not residents, but attended during the day for programs relating to education, care, training or employment (*n* = 155). For this study, the full-time residents and the adults with

ID who attend the day programs will be included in the results. A total of 949 adults (residents and non-residents, ranging from 18 to 92 years of age) received support across the 19 facilities.

Of the 949 adults, 19.2% (*n*=182) were described as having a mild ID, 49% (*n*=465) as having moderate ID and 29.2% (*n*=277) as having severe to profound ID. Level of ID was not provided for the remaining 25 adults (2.6%). All facilities reported that they provided services to adults who presented with various conditions in addition to ID. The most common coexisting conditions of the 949 adults were mental illness at 36.2% (*n*=344) followed by epilepsy 15.8% (*n*=150) and Down syndrome 11.4% (*n*=108) as indicated in Figure 4. The least common coexisting conditions, grouped under 'other' in Figure 4 consisted of Korsakoff syndrome, Guillain-Barré, Spina Bifida, Motor Neuron Disease and Dementia each of which was identified in one adult with ID (0.1%).

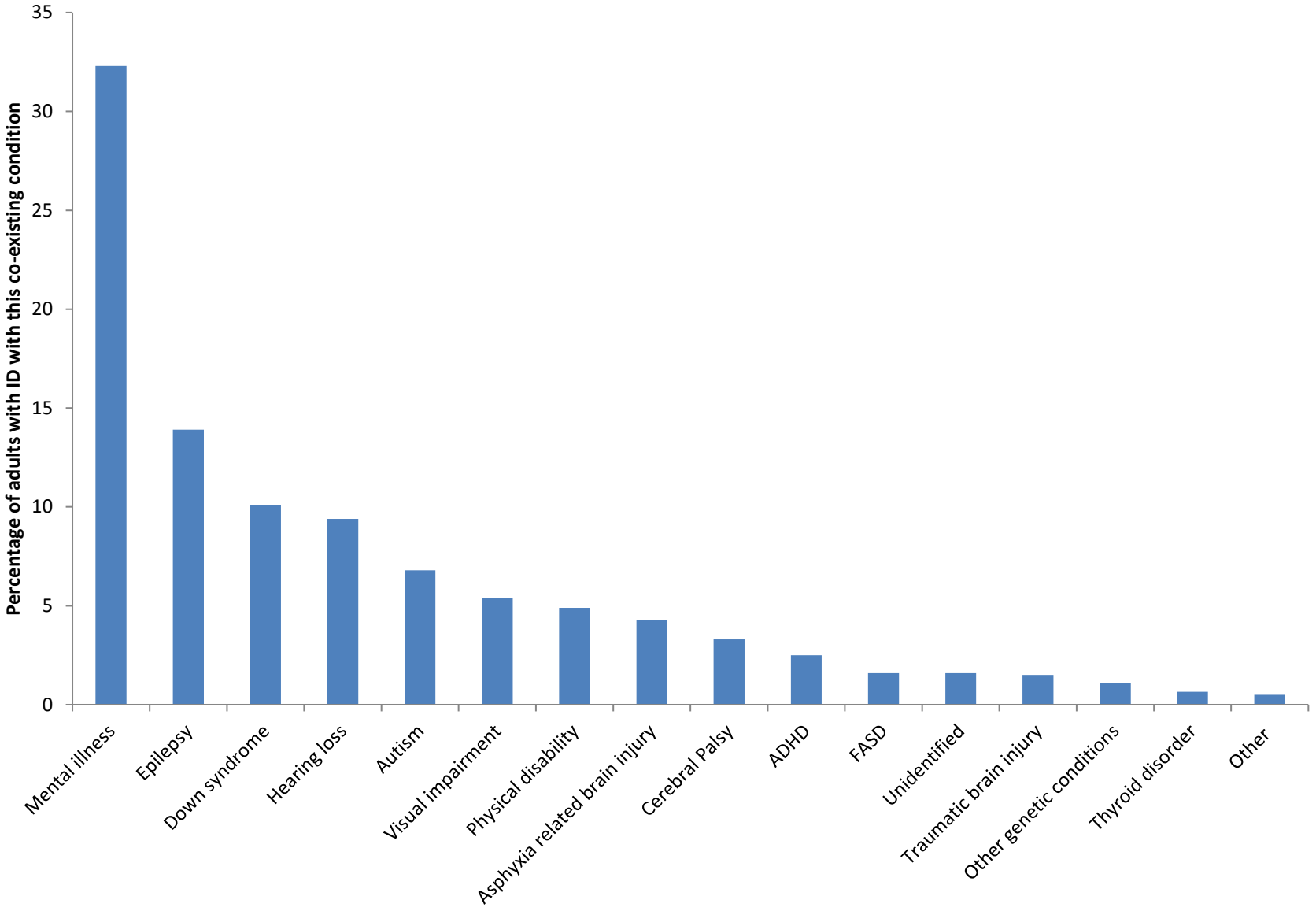


Figure 4. *Percentage of adults with ID with coexisting conditions*.

3.2.2 Communication and behavioural skills of adults with ID

Participants were asked to estimate the number of adults with ID in their facility that possessed a variety of communication skills or challenges relating to receptive language, expressive language, pragmatics and behaviour. Figure 5 provides an overview of these skills and challenges. In terms of overall communication ability, 641 adults (67.5%) were described as being able to understand and communicate effectively, suggesting that 32.5% of adults (*n*=308) are unable to communicate effectively.

When considering receptive language, 24% of adults (*n*=228) were described as having difficulty following instructions, while 31.4% (*n*=298) were described as having difficulty understanding questions. That being said, almost a quarter of the adults (n=231) within seven facilities were exposed to aided AAC in the form of visual resources to aid comprehension, for example, schedules, lists and/or charts.

When considering expressive language, 126 adults (13.3%) were described as having unintelligible speech when attempting to communicate. Both unaided and aided forms of AAC were utilised by the adults to express themselves. Regarding unaided forms of AAC; 89 adults (9.3%) used signs from South African Sign Language (SASL) to communicate. However, 83 of those adults were from the same facility which functions primarily as a centre for the Deaf for persons without ID. More informal methods of unaided AAC, namely gestures and vocalisations were also utilised by 39 adults (4.1%) and 92 adults (7.9%) respectively. Regarding aided forms of AAC, an alternative communication system was used by one adult (0.1%) who wrote on a board to express his/her messages.

In terms of pragmatics and social behaviour, 29.3% (*n*=278) were described as displaying inappropriate social interaction with others, while a further 24.1% (n=229) were described as having behavioural challenges.

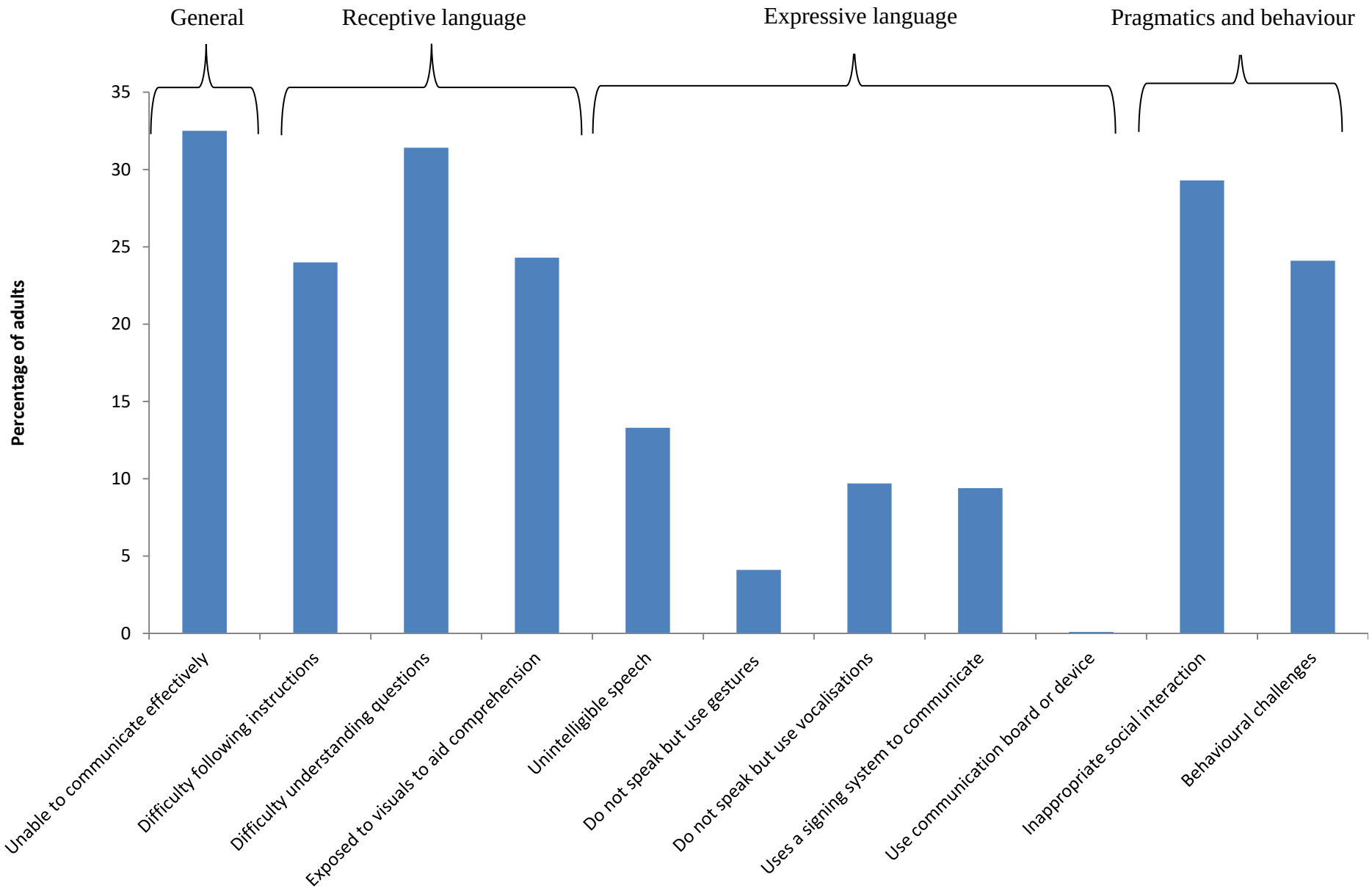


Figure 5. *Overview of communication skills and challenges.*

3.2.3 Literacy skills of adults with ID

Participants were asked to estimate the number of adults who had acquired a range of literacy skills. Figure 6 gives an overview of the number of adults described as having specific levels of reading and writing skills. The levels of reading abilities that were given in this question were not interpreted as mutually exclusive of each other and it seems that many participants categorised adults into more than one level. That being said, 363 adults (38.3%) were described as not being able to read at all, 538 (56.7%) as being able to read environmental print, 192 (20.2%) as being able to read a little, 202 (21.3%) as being able to read some, 142 (15%) as being able to read quite well and 122 (12.9%) as being able to read almost everything or very well. The ability to read environmental print was thus identified as the most common level of reading ability among the adults.

As with the results of reading abilities, the levels of writing abilities that were given in the question were also not interpreted as mutually exclusive of each other, and it seems that many participants categorised adults into more than one level. That being said, 394 adults (41.5%) were described as not being able to write at all, 373 (39.3%) as being able to write words they were frequently exposed to, 134 (14.1%) as being able to write a little, 124 (13.1%) as being able to write some, 95 (10%) as being able to write quite well and 68 (7.2%) as being able to write almost everything or very well. Not being able to write at all was thus identified as the most common level of writing ability among the adults.

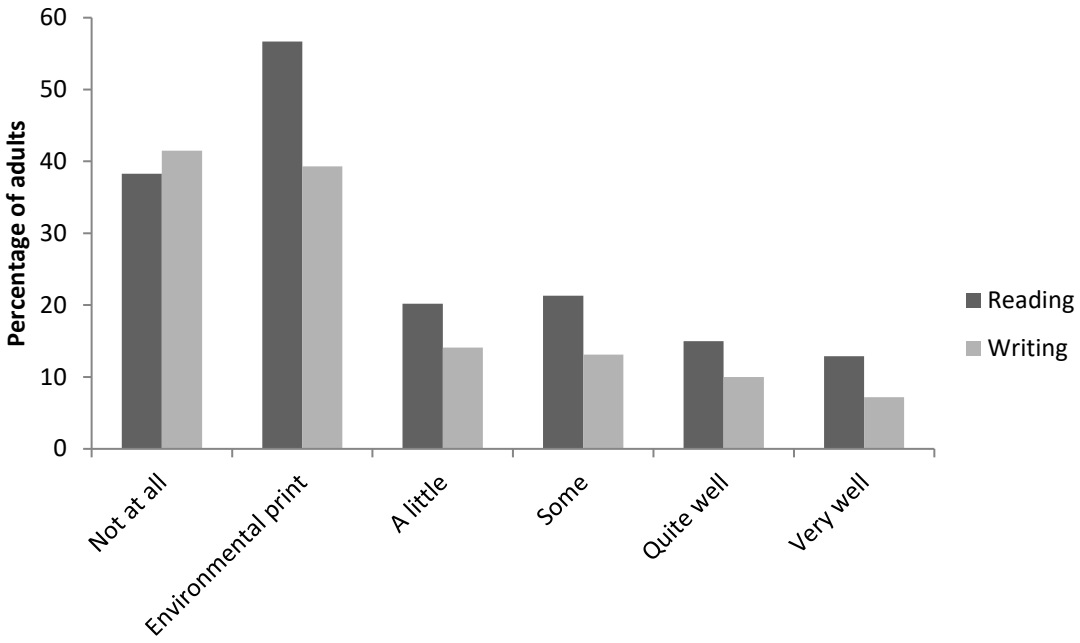


Figure 6. *Adults levels of reading and writing ability as described by participants.*

3.3 Staff in residential facilities and the communication skills and strategies they use

3.3.1 Description of the staff

Participants were asked to provide an estimated number of staff members working directly with the adults as well as their titles. A total of 288 staff members were identified with a variety of 18 job titles, as indicated in Figure 7. Most staff members consisted of home carers, followed by house mothers/fathers or house leaders. None of the participants indicated that a speech-language therapist was employed at their facility.

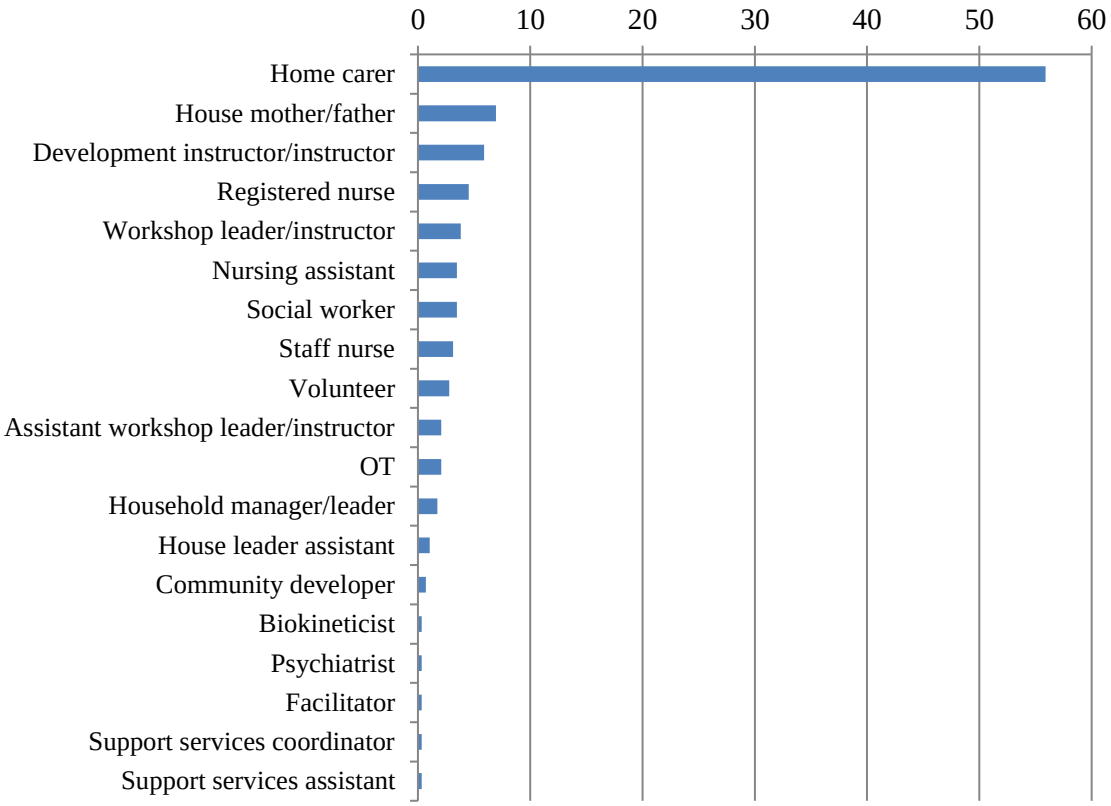


Figure 7. *Overview of staff members employed at residential facilities.*

Residential facilities had a larger number of staff (*m* = 23) compared to group homes (*m* =13.8). The number of staff employed at group homes is however confounded by the fact that four of the group homes were part of a larger centre with a more significant staff compliment than the others in the study. This centre has three to four staff members stationed at each group home as well as 16 staff members working as workshop leaders, assistant workshop leaders or volunteers. They were stationed at various workshops on the premises and work directly with all the adults from all four group homes during the day.

The overall mean of adults-to-staff ratio for all facilities was identified as 1:3. When comparing types of facilities, group homes had a ratio of 1:2.7 while residential facilities had a ratio of 1:3.7, indicating a ratio difference of 1 between the types of facilities.

3.3.2 Communication skills and strategies of staff as indicated by facility managers'

Participants were asked to indicate how true the provided statements were regarding communication strategies used by care staff to support adults with ID and communication

difficulties in their facility. The response options to the statements consisted of "consistently true", "sometimes true", "rarely true" or "never true". Ratings given to perceived use of communication strategies along with the median ratings and interquartile ranges are displayed in Table 5.

Overall, there was a positive response regarding how consistently care staff utilised a variety of communication strategies. Care staff most consistently acknowledged the adults attempts to communicate and encouraged socialisation amongst adults. Care staff were less consistent in providing multiple-choice options, changing their way of speaking to accommodate the adult and using visual support such as gestures or symbols to scaffold understanding. Furthermore, 12 participants reported that care staff did not consistently expect communication from the adults. Of the 14 facilities were AAC was implemented, most participants reported that care staff sometimes supported the use of AAC systems provided to the adults.

Table 5

Perceived Use of Communication Strategies by Care Staff

Item	Consistently true		Sometimes true		Rarely true		Never true		Median[a]	IQR[b]
	n	%	*n*	%	*n*	%	*n*	%		
1. Acknowledge the adults attempts to communicate	17	89.5	2	10.5	0	0	0	0	4	0
2. Provide multiple choice options	12	63.2	6	31.6	1	5.3	0	0	4	1
3. Seldom expect communication from the adults	1	5.3	5	26.3	6	31.6	7	36.8	3	2
4. Change their way of communicating to accommodate the adults	14	73.7	2	10.5	2	10.5	1	5.3	4	1
5. Use visual support to scaffold understanding	12	63.2	2	10.5	4	21.1	1	5.3	4	2
6. Encourage socialization amongst adults	18	94.7	1	5.3	0	0	0	0	4	0
7. Support the use of alternative communication systems provided to the adults [c]	3	21.4	7	50	0	0	4	28.6	3	1.5

[b] The most positive score options on the scale were accorded a score of 4, and the most negative a score of 1. Therefore, the option 'consistently true' was accorded a score of 4 for all items except for Item #3, which was negatively worded. The option 'consistently true' for this item was therefore accorded a score of 1. [b] IQR = interquartile range. [c] A total of 14 respondents answered this question as AAC was implemented at 14 facilities.

3.4 Communication resources and support services available to the staff and adults

3.4.1 Availability of services and training

Of the 19 facilities, one stated that speech and language therapy services were currently available to the adults and staff. These services were provided by the local hospital, where outpatient therapy services could be accessed. It was identified that five facilities (26%) had received formal or informal training regarding how to communicate with the adults or improve their communication skills. The training that was provided was focused on AAC (particularly unaided communication systems, such as the use of signs from SASL or Makaton) and was conducted by internal staff (n = 1), private companies (n = 1), experts in the field (n = 1) or university centres (n = 2). Of the five facilities, one reported that regular (weekly) training was provided, while the others had received once-off training sessions.

3.4.2 Availability of communication resources

Aided AAC systems to support comprehension such as paper-based symbols to label objects, feelings and weather charts, calendars and daily visual schedules were implemented in seven facilities. These resources were made by the staff, or they were acquired during external training from experts, learning institutions or forums. Communication resources to support expressive language were less common with three facilities reporting that communication resources for expression were implemented in their facility. These consisted of SASL training resources and writing material for an adult who communicated by writing down messages. Low technology communication boards or electronic speech-generating devices were not available to adults or staff in any of the facilities.

3.5 The needs of the staff and adults with ID pertaining to communication resources and support services

3.5.1 Perceived need for training to support communication

Participants were asked to indicate to what extent they felt that there was a need for professional development training to enable staff to support the communication of adults. Of

the 19 facilities, 5.3% (*n* = 1) reported no need, 15.8% (*n* = 3) reported little need, 42.1% (*n* = 8) reported some need and 36.8% (*n* = 7) reported extensive need.

3.5.2 *Perceived prioritisation of health and support needs*

Participants were requested to think about various health and support needs provided in a listed format and rank them in order from the most to the least important. Results are portrayed in Figure 8.

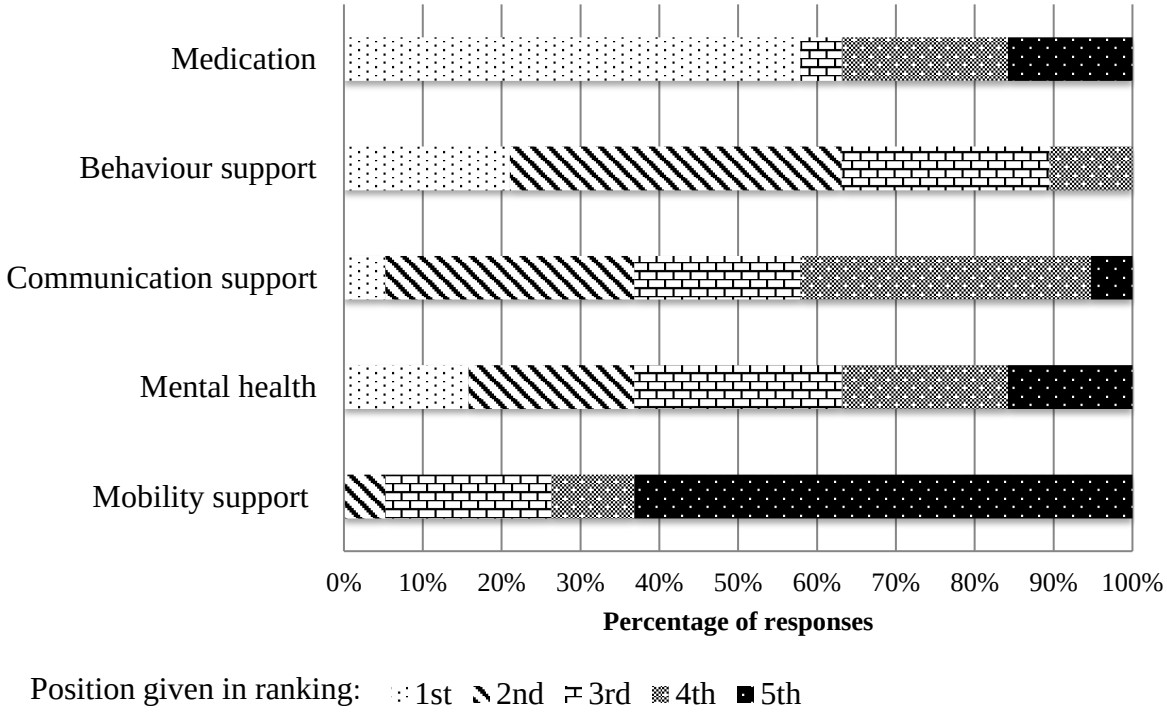


Figure 8. *Participants' ranking of health and support needs.*

Medication was ranked as the most important need most frequently, with 11 respondents ranking it in first place (most important). Behaviour support was ranked as the most important need with the second highest frequency and was also most often ranked as the second most important need. Communication support and mental health needs received relatively similar rankings, with communication support being ranked mostly as either the second or fourth most important aspect to address, whereas mental health was ranked in second, third or fourth place with relatively similar frequency. Mobility support was most often ranked last. The median and interquartile ranks are displayed in Table 6.

Table 6.

Median and interquartile ranks of ranked health and support needs.

	Median	*Interquartile ranks*
Medication	1	3
Behaviour support	2	1.25
Communication support	3	2
Mental health	3	2
Mobility support	5	2

3.6 Themes identified from qualitative responses

3.6.1 Barriers to communication

It was reported by two participants that anti-social and challenging behaviour were common challenges faced in their environments. One participant described how it was challenging for staff to encourage socialisation amongst adults in their facility due to such behaviour. This participant stated; *"encouraging socialisation does not work, anti-social behaviour is a common challenge"*. Another participant described how multiple-choice options were not always offered to adults who were unable to make choices independently as boundaries needed to be set by staff in order to maintain discipline.

Staff shortage presented as an additional barrier to communication. Two participants reported that it was challenging for care staff to provide individual communication support as there was not enough staff available. One participant stated; "visual supports are very limited. We have to produce it ourselves and are short staffed". The other participant further mentioned that they were unable to send staff members on training courses concerning how to support communication due to the fact that they were short-staffed.

3.6.2 Facilitators of communication

Three participants reported that staff members were able to communicate effectively with the adults who had communication difficulties as they had learned over time to identify

and interpret their communication patterns or attempts. One participant stated; *"We have a number of non-verbal folks, but my staff manage communication with them no problem".* Another participant stated, "*…once a client or beneficiary of services is used to the staff and management, they are able to make their needs known more easily and are no longer as anxious and wary of the people assisting them…"*

Two participants reported that activities encouraged by the facility encouraged communication and socialisation amongst the adults. One stated that activities such as sports, game and exercises provided opportunities for social interaction while another participant mentioned communal mealtimes as a facilitator of communication and socialisation: *"(It's) easier to encourage participation in eating, (discussing) what all are eating …".*

3.6.3 Needs of adults with ID

The needs of adults were brought to attention through the responses of four participants. Firstly, it was reported that adults with ID require a holistic living environment; furthermore, a holistic approach should be considered when providing services to them. Secondly, it was described how ongoing care and supervision was needed to avoid bullying and anti-social behaviour amongst adults. Thirdly, a small, nurturing environment was deemed a need for adults. Lastly, ongoing therapies and adult play therapy sessions were suggested as ways to enhance relaxation and provide appropriate stimulation for adults with ID.

3.6.4 Needs of the facilities and staff

It was reported by one participant that funding was needed since financial support by governmental departments was not provided. The facility relied solely on funding received from the adults disability grants which were described as being insufficient. The participant reported;

"*We need the support of DoH (Department of Health), we need the assistance, we play an important role by taking care of the state's responsibility. The residents living here are all abandoned by family and only receive a disability grant of R1780. We are not subsidised by government".*

Furthermore, it was identified by two facilities that staff require appropriate tools to provide communication support, such as visual support material and relevant training. One

participant reported that visual supports to aid comprehension were available at their facility, however they were very limited. It also proved challenging to produce visuals themselves as the facility reported that they were short-staffed and did not have the time to do so.

4. DISCUSSION

The main aim of the study was to describe the communication skills, resources and needs of adults with intellectual disability living in residential facilities in the Western Cape and their support staff, as reported by facility managers. In this section, the results of the study will be discussed in light of current literature.

4.1 Communication skills of adults with ID versus staff skills and communication resources

Nearly one-third (32.5%) of adults with ID receiving services from the responding organisations were identified as not being able to understand or communicate effectively. This figure suggests that a number of adults in residential facilities in the Western Cape would benefit from some form of AAC. This is supported by McKenzie et al. (2013) who found that significant communication difficulties exist among adults with ID in Western Cape. This figure is also similar to that of Sutherland et al. (2014), who identified that 28.8% of adults with ID in facilities or assisted living programmes in New Zealand were candidates for AAC intervention.

Since over three-quarters of the adults were described as having either moderate or severe ID, and the severity of the ID is often linked with communicative ability, difficulties in this regard were expected. That being said, a larger percentage of adults with communication difficulties was expected due to the fact that most adults were reported as having either moderate or severe ID.

4.1.1 Receptive communication

Regarding receptive support, AAC strategies that support the comprehension of questions and following of instructions would prove beneficial to 31.4% and 24% of adults respectively. Interventions in AAC targeting receptive language could assist the adults in adapting to a particular environment, provide cues for independent task completion as well as develop language skills (Dodd, 2005). Communicating in a visual and verbal format as opposed to purely verbal proves more effective for this population as sign, object or symbol recognition is required rather than recall skills which are often impaired in adults with ID

(Lal & Bali, 2007). Furthermore, visual symbols provide a more concrete and permanent form of visual support as information presented auditorily is transient (Dodd, 2005).

Visual supports, for example, daily programmes, duty and stimulation rosters, feelings and weather charts, calendars and menus were implemented by most of the facilities who utilised both aided and unaided modes of AAC to augment comprehension. Such AAC aids have found to be beneficial in environments frequented by adults with ID as they increase understanding of what and how to do something in a given environment, enable them to understand a communication partner's message (enhancing social interactions), reduce anxiety and promote personal independence (Lal & Bali, 2007; Lindsay, 2011).

Marrus and Hall (2017) suggest that impairment in language comprehension is often linked to psychiatric disorders. Mental illness is frequently experienced by adults with ID and was reported by participants as the most frequently occurring co-morbid condition. Comprehension supports provided to adults experiencing symptoms of mental illness could assist with adaptive functioning within their daily environment by augmenting their understanding of the world around them as well as allow for engagement in counselling or psychotherapy. Since abstract language is used when communicating about emotions, visual aids could assist in concretising such concepts and consequently increase understanding.

The seven facilities that reported using aided forms such as schedules or charts obtained or learnt about them during training sessions, via disability associations or from experts in the field, demonstrating the importance of staff training and consistent interactions with knowledgeable professionals in the facilitation of language skills. Furthermore, these resources were mostly implemented and maintained by the OT, social worker, or visiting social work students at the facility. Responses from the participants suggest that care staff are not as involved in this process due to time constraints or lack of appropriate knowledge. It may also be suggested that OTs and social workers have more knowledge of communication support through their respective graduate programmes or possibly an increased awareness of the importance of communication support for adults with ID in residential facilities.

The remaining twelve facilities reported that aided forms of AAC to support language comprehension were not available at their facility. This may be due to these facilities,

possibly not having professionals such as OT's, social workers or speech-language therapists to provide develop and maintain such resources.

Care staff more often used unaided, informal gestures as a means of augmenting receptive language with 63.2% of participants reporting that gestural supports such as pointing to implied object or person were consistently used by care staff. Furthermore, additional strategies such as changing their way of communicating to accommodate the adult (for example, slowing down their speech) and providing multiple-choice options were reported as being utilised consistently by 73.7% and 63.2% of participants respectively. This may be attributed to the fact that informal, unaided AAC strategies present as a natural way of supporting individuals with communication difficulties and do not require any specific materials, knowledge or training to implement their use (ASHA, 2019).

It is promising that care staff expose the adults to such strategies in most facilities to support communication. That being said, informal systems may prove limiting when referring to people or objects outside of their immediate environment. The use of more formal systems to augment comprehension such as SASL or Makaton could allow for comprehension of a larger variety of messages and support the development of spoken language (Dodd, 2005). However, the implementation of a formal system requires training to teach its use, which would only prove possible with sustainable staff training and provision of appropriate resources.

4.1.2 Expressive communication

When considering expressive language, 13.3% of the adults were identified as being unintelligible while 4.1% and 9.7% were reported as being unable to speak but used gestures or vocalisations respectively. Firstly, this indicates how AAC systems or strategies that augment as well as provide an alternative to speech are necessary within this setting. Secondly, these findings are in line with Lindsay (2011) who states that individuals with ID and communication difficulties often rely on unaided AAC strategies such as informal gestures, facial expression or vocalisations to communicate with familiar communication partners. Interpersonal relationships are "one of the core elements that impact on quality of life" with familiar communication partners playing an essential role in the adults social network, decreasing feelings of loneliness and providing opportunities to practise acquired AAC skills (Stancliffe et al., 2010; Dalton & Sweeney, 2011, p. 23).

Participants stated how through interactions with the adults, staff members had learned over time to recognise and interpret the adults communication patterns or attempts in order to meet their needs. By recognising communication methods, interactions can be supported by familiar communication partners regardless of the level of communicative ability and adults will be encouraged to continue expressing themselves rather than attempts going unnoticed or being unsuccessful resulting in abandonment (Dalton & Sweeney, 2011).

As informal gestures and vocalisations can often only be interpreted by familiar partners, they may prove limiting when entering more unfamiliar environments (Goldbart & Caton, 2010). Should the individual transition to a vocational setting or new residential environment where communication partners are no longer familiar with their communication style, it may take time before they are understood. Furthermore, communicating novel messages or about things not within the immediate environment may prove challenging for individuals using informal methods of communication as there is no object or person to reference.

The formal systems implemented in the facilities to support expressive language consisted of both aided and unaided modes. Signing systems such as SASL or Makaton was reported as being used by 9.3% of the adults. Although it was not implemented by any of the facilities, key word signing is an alternative unaided AAC system used where speakers "simultaneously support the primary content words in their speech with manual signs", thus entailing less linguistic complexity than SASL (Rombouts, Maes, & Zink, 2018, p. 21).

Signing systems (i.e. SASL, Makaton and key word signing) prove effective within this population as adults with intellectual disabilities may find it easier to produce and combine hand movements than use speech alone (Rombouts et al., 2018). Furthermore, for adults with more significant motoric and linguistic challenges, key word signing may prove more appropriate as fewer demands are placed. Individuals communicating with signs may however experience challenges during interactions with unfamiliar communication partners who do not have the sufficient skills to communicate using a signing system (Sigafoos & Drasgow, 2001).

Aided AAC strategies such as the implementation of a communication board or speech-generating device was reportedly used by only one adult who wrote down his

messages to communicate. Stancliffe et al. (2010) reported similar results in their study in the United States of America where, of the 3003 adults who used a specific non-speech means of expression, only 3.4% were found to be using aided AAC systems whereas gesture or body language (91.4%) and sign language (5.2%) were more commonly used. The lack of aided AAC may be attributed to the fact that such systems need to be personalised by a speech-language therapist and designed to suit the needs of the individual specifically. Aided AAC strategies to augment comprehension such as schedules or charts, on the other hand, require less personalisation and may thus be more readily available.

In the current study, no adults were reported as using a graphic symbol-based (picture-based) AAC system to communicate. Such aids may be compiled using pictures from a formal picture library (e.g. Picture Communication Symbols, Symbolstix) or from various other sources, such as own photographs or clipart images from the internet. Typically, one picture represents one concept, and each picture is accompanied by a written word or phrase. Such AAC systems may prove beneficial for adults with ID as they may enable them to communicate a variety of messages within a community setting with a range of familiar and unfamiliar communication partners. Typically, comprehension is facilitated when partners are literate and can read the gloss or label of the picture symbol, since picture symbols themselves can be ambiguous in meaning.

It is to be expected that most adults who would potentially use an aided AAC system would make use of a language representation method using single-meaning pictures due to the number of adults who were reported as being not fully literate. That being said, since many of the adults were reported as being able to read and write familiar words or environmental print, there is potential for adults to use alphabet- or written word-based AAC systems to communicate things in the current environment. However, it is unknown whether those who were reported as being able to read and write environmental print are the same adults who have communication difficulties.

Both aided and unaided modes of communication can be of benefit for language expression, depending on the communication situation. Since communicative success across a variety of environments and communication partners often depends on type and mode of AAC, in some situations an aided mode may be deemed more effective while in others an

unaided mode is more effective (Sigafoos & Drasgow, 2001). There are however benefits and drawbacks of each.

Speech-generating devices, a type of aided AAC system, can provide voice output, allowing for easy integration into everyday environments with familiar and unfamiliar communication partners since partners are already familiar with the linguistic system being used (Mirenda, 2001). There is also an increased availability due to technological developments in mobile technologies as a cell phone loaded with an appropriate communication application could be used to generate speech as opposed to a more costly dedicated AAC device. That being said, some aided AAC systems are complex to operate and have poor ease of usability resulting in abandonment (Salminen, Petrie, & Ryan, 2004). Furthermore, these devices require individualised personalisation by a speech-language therapist who might not always be available.

On the other hand, unaided systems (i.e. SASL, Makaton and key word signing) are advantageous as they do not require any additional equipment when being used to communicate. That being said, individuals require adequate motor control for producing signs as well as communication partners who can interpret the intended message (American Speech-language-Hearing Association [ASHA], 2019). Communication partners would thus require training or resource materials to be able to learn and teach the sign language system which would involve adequate funding and time resources (Rombouts et al., 2018).

Current best practice in AAC emphasises the need for and value of multimodal communication. The use of multiple modes makes for a more efficient and effective communicative exchange as some messages that could be easily interpreted by the communication partner are often quicker and easier to produce using unaided gestures or signs (Sigafoos & Drasgow, 2001). Furthermore, malfunctioning or unavailability of the aided AAC system or device may require the individual to rely on unaided modes of AAC.

Literature suggests that staff working directly with adults with ID find it challenging to implement and maintain the use of aided AAC systems, experiencing barriers due to a variety of reasons. The barriers mentioned by the participants were in line with barriers stated by Beukelman and Mirenda (2013) in the Participation Model, particularly regarding policy, facilitator skill and facilitator knowledge.

Responses from participants highlighted; (1) a lack of professionals delivering AAC services in adults' settings, (2) no or insufficient training on how to support and facilitate individuals using AAC, (3) poor availability of AAC devices or resources and (4) lack of funding. The AAC systems and strategies that were in place in the current study existed either because (1) sustainable training was provided (i.e. weekly SASL training), (2) individuals knowledgeable in the field of AAC provided the resources, or (3) the implementation of the system was not dependent on training or funding (i.e. writing down messages to communicate). This highlights the need for education and advocacy around AAC service provision in the Western Cape in order to meet the communicative needs of adults with ID in residential facilities and live up to the obligations of UNCRPD.

4.1.3 Socialization and challenging behaviour

Almost one-quarter of the adults were described as having behavioural challenges. This proportion was to be expected as the percentage is relatively similar to the number of adults reported as having communication difficulties. Behaviour support was also identified as the second highest health support need after medication by participants. Furthermore, care staff reportedly found it difficult to encourage socialisation among the adults due to challenging behaviour. Challenging behaviour is however utilized as a means of expression for some individuals with communication difficulties and ID and may be the only way to convey their needs. Care staff should thus interpret challenging behaviour as communicative rather than defiant and acknowledge all attempts to communicate (Dalton & Sweeney, 2010).

That being said, the majority of facilities (89.5%) reported that they did acknowledge all attempts to communicate from the adults, however they may not be aware that challenging behaviour is, in fact, a form of communication for the adults. Training or support from a relevant professional in AAC could educate staff on interpreting challenging behaviour as a communication method. Furthermore, improving communication through AAC strategies or systems could assist in managing challenging behaviour by reducing frustration, allowing for access to learning and personal development as well as increasing social participation (Hutchins & Prelock, 2014).

The way care staff interpret challenging behaviour may present as an opportunity barrier, as mentioned in the Participation Model due to them viewing these communicative attempts

as a form of non-compliance. Additionally, reduced expectation of the adults abilities could also result in more limited opportunities for successful communicative interactions as one facility (5.3%) stated that care staff seldom expect communication from the adults while another five (26%) stated that care staff sometimes seldom expect communication from the adults (Beukelman & Mirenda, 2013). Healy and Noonan Walsh (2007) found that only 27% of nurses consistently expected communication from adults with severe and profound ID.

Challenging behaviour may also occur as a result of limited self-determination or lack of feelings of control over life (Hutchins & Prelock, 2014). Opportunities for self-determination and personal autonomy regarding daily as well as more significant decisions are often limited or absent for this population, particularly within residential centres as opposed to group homes (Hutchins & Prelock, 2014). By providing a means of functional communication using AAC, opportunities for decision-making can be provided to adults with ID, increasing active participation in their lives, avoiding challenging behaviour and discouraging learned helplessness through persistent exclusion (O'Donovan et al., 2017).

4.1.4 Communication-related needs

Communication support was ranked as the third-highest health and support need by participants, while behaviour support needs due to challenging behaviour was ranked as the second highest. This should be considered alongside communication needs as challenging behaviour often results from frustration caused by communication difficulties (Hutchins & Prelock, 2014).

Most participants (79%) indicated that there was some or extensive need for professional development training to enable staff to support the communication of the adults. Only a few participants reported that staff had attended AAC related training and most that did stated that it was not ongoing or currently implemented. A study conducted by Dalton and Sweeney (2011) identified training as a considerable need to enable support staff to implement communication supports in a similar setting. However, if such training was offered, short-staffing could potentially result in staff not being able to attend training sessions.

Although participants indicated that training was needed, they also stated that staff were using many more informal communication support strategies already quite consistently. The

facility managers may feel that knowledge of more formal AAC strategies and systems (e.g. signing systems or specific partner support strategies such as modelling or prompting) would be more beneficial to the staff and adults and ensure a level of consistency across approaches used by staff when providing communication support (Dalton & Sweeney, 2010).

When considering the reasons for not all participants stating that training was needed, we could consider the practice barrier as mentioned by Beukelman and Mirenda (2013). Long-standing practices may not have included training to support the adults communication or possibly not encouraged the facilitation of communication due to reduced expectations of the adults capabilities. Alternatively, since staff can interpret the communicative behaviours of the adults and to an extent communicate successfully with them, they may not think communication support such as AAC is necessary.

Furthermore, a need exists for access to specialist AAC support such as a speech-language therapist as well as support from alternative disciplines such as occupational therapists or social workers. Staff require guidance from a speech-language therapist regarding the implementation of personalised AAC systems, while other members of the multi-disciplinary team prove beneficial in implementing and maintaining environmental visual supports accessed by the adults during daily activities. Implementing and maintaining AAC strategies prove challenging to staff due to high staff-to-adult ratios affected their ability to spend additional time with an adult to facilitate communication.

Dalton and Sweeney (2011) reported similar findings where care staff in residential facilities for adults with ID felt unable to provide communication support due to a lack of knowledge and resources from a relevant specialist. On the other hand, services may be available but facilities may be unaware of how to access them, or they may be unaware of the role of the speech-language therapist, resulting in uncertainty regarding whom to contact for such services. Rombouts et al. (2018) further indicated that care staff benefitted more from formal training as opposed to in-service training when being taught how to implement AAC strategies. To avoid the distractions that may potentially occur during in-service training, formal training sessions to teach the use of AAC strategies should be conducted.

5. CONCLUSION

The purpose of this study was to describe the communication skills, resources and needs of adults with ID in residential facilities in the Western Cape and their support staff. Data was acquired through self-administered questionnaires completed by facility managers.

Overall, it was identified that approximately a third of nearly 1000 adults in residential facilities in the Western Cape were unable to communicate effectively. The adults ranged in age and severity of ID however the severity was most often described as being moderate. The facilities employed a variety of staff members consisting mostly of care staff and an average ratio of staff to adults at 1:3. All facilities provided services to adults who presented with various conditions in addition to ID with the most common being mental illness. Also, more than half of the facilities offered non-residential day services to adults with ID in the community pertaining to education, care, training or employment skills.

Aided AAC to augment comprehension was implemented by some facilities in the form of visual schedules or charts which were obtained from individuals or organisations knowledgeable in AAC. Many facilities did not report such aids to be available. A need thus seems to exist for the implementation of such visual aids to facilitate language comprehension. Furthermore, such strategies were more often maintained by the OT or social worker at the facility as opposed to the care staff due to time limitations. Care staff mostly used unaided AAC strategies in the form of informal gestures to augment their language possibly since these strategies present as a natural way of supporting individuals with communication difficulties and do not require any specific materials, knowledge or training to implement their use.

With regards to expressive language, adults with no or limited speech most often relied on informal, unaided AAC strategies such as gestures, facial expression or vocalisations to communicate. While staff were reported to consistently respond to communication attempts and also to scaffold expression by offering choices, communication breakdowns may still have occurred due to the use of these informal, non-linguistic methods of communication. This however required interpretation of the communicative acts by the care staff serving as familiar communication partners.

Few facilities implemented a formal mode of aided or unaided AAC to support expressive language. While a small number of facilities encouraged formal signing systems such as SASL or Makaton, there were no aided AAC systems identified with a single picture or semantic compaction language representation method. Furthermore, only one adult used an alphabet-based system where he wrote messages down. A dearth was thus identified regarding access to formal symbol-based AAC systems for adults with ID in this setting. Responses from the participants suggested that this was due to a variety of environmental barriers relating to a lack of staff skill and knowledge and limited access to appropriate professions such as speech-language therapy for AAC related training or support.

Further barriers to supporting effective communication in adults with ID were reported by participants namely; behavioural challenges of the adults, staff shortages, time limitations for training and implementation, lack of funding and the unavailability of appropriate communication resources. On the other hand, practices that facilitated communication were also identified. Participants reported that most care staff (1) interpreted informally the vocalisation and gestures from the adults as communicative acts, (2) acknowledged that communication might take on a variety of forms (3) changed their way of communicating to accommodate with the adult (4) used visual support such as gesture to support the understanding of language and (5) encouraged socialization amongst the adults.

Broadly, a need exists for aided AAC to support the comprehension and expression of language for adults with ID in residential facilities. Furthermore, there is a need for staff who support communication to obtain knowledge and skills in more formal AAC strategies through ongoing training. Lastly, a need exists for access to professionals who are knowledgeable and skilled in AAC to provide individualised support as well as a need for support from the multi-disciplinary team to implement and maintain more general visual supports due to staffing and time limitations on the part of the care staff.

5.1 Strengths of the study

This study was the first to attempt to describe the communication skills, resources and needs of adults with ID in the Western Cape and their support staff. This is important as the provision of services within residential facilities for adults with ID in developing countries has not been widely researched. Furthermore, a previous study conducted with the same

population and participants had established that communication needs are not being met (McKenzie et al., 2013). The current study provides further insight into what these communication needs are and identifies barriers and facilitators that influence the meeting of these needs.

The development of the questionnaire can be regarded as a strength. The initial questionnaire was scrutinized by a variety of professionals working with adults with ID as well as experts in the field. The resulting questionnaire was deemed contextually appropriate with participants stating that they were able to complete it without difficulty. Furthermore, a variety of residential facilities (residential centres, group homes and mixed facilities) participated in the study across all districts in the Western Cape which resulted in a more representative sample.

5.2 Limitations of the study

The limited sample size is a methodological constraint of this study. Although comprehensive sampling was attempted, the results obtained from this study cannot be generalised to the entire population. The results serve only to highlight the main avenues of enquiry in order to better understand the communicative skills, resources and needs of adults with ID and their care staff.

Also, the responses provided by the participants regarding the communication skills of the adults as well as the strategies used by care staff offered insight and information from their perspective only. Additional perspectives gained from care staff working directly with the adults could be acquired through methods such as a focus group. This may allow for a more comprehensive perspective as to why the implementation of communication supports poses challenging in this setting. Furthermore, participants may have responded to certain questions in what they perceived to be a socially desirable as they may have felt that the results could directly reflect on their effectiveness in their job as the facility manager.

In the completion of Questions 20 to 31 in the questionnaire regarding reading and writing skills, the levels of literacy abilities that fell between the two extremes (cannot read/write at all and can read/write very well) were not interpreted as mutually exclusive of each other. It seems that many participants categorised adults into more than one of these

levels. The interpretation of the results of this section should thus be treated with caution. Should the questionnaire be utilised for further studies, the instructions provided for these items require clarification.

Although the questionnaire did allow participants the opportunity to provide comments at certain questions in an attempt to obtain more descriptive responses (and further highlight concerns unknown to the researcher), only a small number of participants did provide comments. Therefore, further probing into the reasons for the participants responses was limited.

5.3 Clinical implications

Communication needs exist among adults with ID. Findings from the current study support the notion that the deployment of AAC practitioners within this setting is necessary to meet the communication needs of the adults as well as the support staff working with them. By meeting this need, the human right to communication can be upheld for adults with ID and CCN, autonomy is encouraged and self-advocacy can occur. Furthermore, an AAC practitioner can ensure that social barriers are adequately addressed and maintained through knowledge sharing, allowing a social model of disability to be upheld within the facility. It should however be noted that consistent support staff training will prove more valuable than individual intervention from an AAC practitioner due to the more frequent communicative interactions between the support staff and adults.

Most staff were relatively consistent in accommodating adults with communication difficulties and provided a variety of communication support strategies during interactions. A lack of aided AAC methods however existed possibly due to limited support from speech-language therapists who typically develop these tools as well as a lack of funding to acquire AAC systems or devices. There is thus a need to make such systems available to the adults and staff as well as a need for relevant training in order to successfully implement aided AAC methods.

Results from the study indicated that care staff utilised some communication support strategies more consistently than others during interactions with the adults. Clinically, it would be significant to discover the reasons behind this and provide suggestions as to how

support can be provided (when necessary) in order to increase the consistency both within and across strategies. This would assist the individuals who work most directly with adults with ID in facilitating communication to a point where participation and access to a range of desired activities are possible.

Participants reported challenging behaviour as a frequent concern. AAC intervention is needed to provide a means of functional communication to adults with ID who experience frustration due to unmet needs and desires. Furthermore, training pertaining to the interpretation of challenging behaviour as communicative acts could be carried out in an attempt to shift the perceptions of staff that adults displaying challenging behaviours are being oppositional or non-compliant.

5.4 Recommendations for further studies

The information received in the current study from the facility managers could be verified by comparing it to information provided by the staff and adults themselves. Information could be obtained from the staff by means of a questionnaire or interview while information could be obtained from the adults using methods such as AAC tools and/or strategies as well as the use of closed-ended questions. This would assist in determining whether the perceptions of the facility managers are in line with what is happening within this context in reality. Furthermore, focus groups could be conducted with staff in order to gain more qualitative information, and thus a deeper understanding of the facilitators or barriers care staff experience and how they influence interactions with the adults.

In order to obtain a more accurate representation of the current communicative and related skills of adults with ID and the staff, observations that take into consideration the adult with communication difficulties, the environment and the communication partner could be conducted. The Augmentative and Alternative Communication Profile (Kovach, 2009) is one such observation tool that could be utilized.

In order to gain more generalizable and representative results, the current study needs to be replicated with larger sample sizes. The questionnaire could also be used in alternative provinces in SA, allowing for a more comprehensive description of the provision of communication-related resources and services for adults with ID across the country.

Additional inferential statistical analyses could then also be undertaken to identify factors that may influence the extent to which communication needs of adults with ID are met, for example, size of the facility, adult: staff ratio, or the severity of ID that adults present with.

The questionnaire used in this study could also be used in an alternative format (e.g. face-to-face or telephonic interview). This would provide opportunities for more descriptive responses, allowing us to find out more about the barriers and facilitators to effective communication for adults and staff as perceived by facility managers.

Lastly, in order to counteract the bias that results from socially desirable answers, foils could be built into the questionnaire. In order to identify such bias, a social desirability bias scale such as the Marlowe-Crowne Social Desirability Scale could be implemented (Crowne & Marlowe, 1964).

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Appendix A

Ethical Clearance Letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

30 November 2018

Dear Ms Howes

Project:	**Communication skills, resources and needs of adults with intellectual disability living in residential facilities in the Western Cape and their support staff: A descriptive study**
Researcher:	**A Howes**
Supervisors:	**Dr K Tönsing**
Department:	**Centre for Augmentative and Alternative and Communication**
Reference number:	**18298533 (GW20181118HS)**

Thank you for the **well written** application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at a meeting held on 29 November 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

pp

Prof Maxi Schoeman
Deputy Dean: Postgraduate and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

cc: Dr C Tönsing (Supervisor)
Prof J Bornman (HoD)

Appendix B

Information letter and consent form

Information letter

The Facility Manager Date:_____

(Facility name and address)

Dear _____ (name of participant)

RE: Participation in a research study

My name is Alice Howes. I am currently enrolled for a Master's degree in Augmentative and Alternative Communication (AAC) at the University of Pretoria. I am currently conducting a study entitled: *Describing the communication skills, resources and needs of adults with intellectual disability in residential facilities in the Western Cape and their support staff.*

The study aims to describe the communication skills, communication resources and communication needs that adults with intellectual disability and the support staff working with them may have. The study focuses particularly on adults with intellectual disability and support staff at residential facilities.

I would like to invite you to participate in this study.

Reason for the study
Individuals with intellectual disability (ID) often experience communication difficulties regarding speech production and the understanding and use of language. By looking into the communication and related (literacy, behaviour and social) skills of adults with ID, we can document the number and characteristics of individuals who require communication support in such facilities. Also, by exploring the communication skills and strategies used by staff, we can determine their current knowledge and skills in facilitating successful communication. Lastly, by looking into available communication resources and supports, we can establish if and how these resources and supports are being used and also identify additional needs for such supports and resources in residential facilities for adults with ID.

What will be expected if you choose to take part in the study?
You will be required to complete a questionnaire about the facility itself, the residents and the staff. The questionnaire consists of four sections and contains fixed questions with the option to further discuss certain items. It will take approximately 30-45 minutes to complete. I would like to ask that you return the questionnaire within 2 weeks of receipt. If you are agreeable, I would also be grateful for your contact details in order for me to follow up on some of your answers telephonically if necessary. However, this is not a prerequisite to your

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Email saak@up.ac.za
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Fakulteit Geesteswetenskappe
Lefapha la Bomotho

participation. No contact will be made with the staff or adults with ID

What are your rights as a participant?
You have a free choice as to whether or not you want to take part in the study. There will be no negative consequences if you do not want to take part. You can stop being part of the study at any time by letting me know at any point in the research study. Any information you may already have provided will be immediately destroyed. When I write or speak about the results of the study, I will make sure that your name or the facility's name is never mentioned so that your privacy is protected at all times. The information provided by you on the questionnaire or any further information provided telephonically or via email will be accessed only myself (the researcher), a research assistant, and my supervisor.

What are the risks and the benefits?
At no time during your participation in this study will you be at risk of any harm, whether you decide to take part or not. Potential benefits may include broadening our understanding of the current communication practices between staff and residents with communication challenges at residential facilities. This can assist in identifying needs for additional communication supports and resources to improve services for individuals with ID in such settings.

Who will have access to the results of the study?
The data will be stored in hard copy and electronic format at the University of Pretoria in the Centre for Augmentative and Alternative Communication for 15 years. The data obtained from the research will be used for writing a Master's mini-dissertation, writing scientific papers and possibly for presentation at professional conferences and seminars. A summary of the results will be made available to all interested participants or stakeholders. Your completed questionnaire may be re-used for analysis only once your consent has been obtained again.

Do you want to take part?
Please complete the consent form attached to tell me if you would like to take part or not. Please feel free to contact me or my supervisor if you have any questions about this study. I look forward to receiving your response.

Kind regards,

_____ Date_____

Alice Howes (Student)
alicehowes13@gmail.com
0736031540

_____ Date_____

Kerstin Tönsing (Supervisor)
Centre for Augmentative and Alternative Communication

kerstin.tonsing@up.ac.za
012 420 4729

Participant Informed Consent: Reply slip

Name of participant: _____

Name of facility: _____

Project title: *Describing the communication skills, resources and needs of adults with intellectual disability living in residential facilities in the Western Cape and their support staff, as reported by facility managers*

Researcher: Alice Howes
Master's Student
Centre for AAC
Cell: 073 603 1540
Email: alicehowes13@gmail.com

Supervisor: Kerstin Tönsing
Centre for AAC
Tel: 012 420 4729
Email: Kerstin.tonsing@up.ac.za

I, _____
(Name and surname)

☐ agree to take part in the research study, as mentioned above, conducted by Alice Howes under the supervision of Kerstin Tönsing. My consent is voluntary, and I understand that I may withdraw from the study at any time. I understand that the data obtained from the questionnaire may be used for training and conferences and may be re-used for further analysis with my permission. I understand that all data obtained from the questionnaire will be treated confidentially that the data will be stored for 15 years at the CAAC.

OR

☐ do not agree to take part in the research study

Signature: _____ Date: _____

Appendix C

Questionnaire regarding the communication skills, resources and needs of adults with ID in residential facilities

Questionnaire on communication skills, resources and needs of adults with intellectual disability (ID) in residential facilities in the Western Cape and their support staff

Section A: Background information on facility and adults

1. Your position in the organisation_____

2. Please specify the type of facility (please tick all that apply)

	Residential centre
	Group home
	Mixed residential centre and group home
	Other (please describe)_____

3. Please describe the staff working directly with adults with ID at the facility

Estimated number of staff

	Home carer
	Nursing assistant
	Staff/enrolled nurse
	Registered nurse
	Physiotherapist
	Occupational Therapist (OT)
	Speech-Language Therapist
	Other (Please describe)_____
	_____

4. In total, how many adults with ID are currently receiving support from your facility?

_____

5. Do you currently provide services to adults with ID who do not live at the facility but attend during the day? Services may include education, care, training and/or employment

Yes	No

If so, how many adults receive such services?_____

6. What is the age range of the adults at your facility?

From ____ (youngest) to ____ (oldest) years of age

7. By your estimate, how many of the adults have the following severity of ID. (Since not all adults may have received formal diagnoses, this can also be based on perceived ability)

	mild intellectual disability
	moderate intellectual disability
	severe to profound intellectual disability

8. By your estimate, how many of these adults have the following coexisting/comorbid conditions? (Since not all adults may have received formal diagnoses, this can also be based on observations and/or perceived ability). This would include those with **and** without assistive devices such as spectacles, hearing aids or wheelchairs.

	Cerebral palsy and ID
	Autism and ID
	Mental Illness and ID
	Physical disability (excluding cerebral palsy) and ID
	Visual impairment and ID
	Hearing loss and ID
	Epilepsy and ID
	Down Syndrome and ID
	Attention Deficit Hyperactivity Disorder (ADHD) and ID
	Foetal Alcohol Syndrome (FASD) and ID
	Other (please describe)_____
	_____

Section B: Communication skills and related skills of adults with intellectual disability

Communication ***By your estimate, how many adults:***	Estimated number
9. can understand and communicate effectively	
10. have difficulty following instructions *e.g. "bring a chair"*	
11. have difficulty understanding questions *e.g. "where is your cup?"*	
12. can produce speech, **but** it is not understandable	
13. do not speak **but** use gestures to communicate *e.g. pointing to or leading to tap to request water*	
14. do not speak **but** use vocalisations to communicate *e.g. grunting, crying, laughing or squealing to express emotions, needs or desires*	
15. use signs to communicate *e.g. South African Sign Language*	
16. use a communication board or device to communicate. Please specify type:_____	
17. are exposed to pictures to support their understanding *e.g. visual schedules, rules and routines*	
18. have behavioural challenges *e.g. display self-injury, aggression or inappropriate behaviour*	
19. display inappropriate social interaction with others	

Communication ***By your estimate, how many adults:***	Estimated number
e.g. have difficulty initiating or maintaining a conversation and/or say inappropriate or off-topic things and/or avoid participating in interactive games	

Reading ***By your estimate, how many adults:***	Estimated number
20. cannot read at all	
21. can read environmental print *e.g. logos of popular brands such as "Coca-Cola"*	
22. can read a little *e.g. some single words only*	
23. can read some *e.g. some simple sentences*	
24. can read quite a lot/ quite well *e.g. some simple/short stories*	
25. can read almost everything/very well *e.g. novels, newspapers, magazines*	

Writing ***By your estimate, how many adults:***	Estimated number
26. cannot write at all	
27. can write words that they are frequently exposed to *e.g. their name or popular logos*	
28. can write a little *e.g. some single words only*	
29. can write some *e.g. some simple sentences*	
30. can write quite well *e.g. some simple/short stories*	

31. can write almost everything/very well *e.g. longer passages or stories*	

Section C: Communication skills of <u>care staff</u> working directly with adults with intellectual disability

Please indicate how true the following statements are regarding communication strategies used by care staff to support adults with ID and communication difficulties. Please tick the appropriate block.

Care staff:	Consistently true	Sometimes true	Rarely true	Never true	Comments
32. acknowledge the adults attempts to communicate, *e.g. respond to pointing, vocalisations*					
33. provide multiple-choice options, *e.g. "do you want bread or porridge?" or "would you like to sit outside or watch TV?"*					
34. seldom expect communication from the adults					
35. change their way of communicating to accommodate the adult, *e.g. slow down their speech or repeat the most important words*					
36. use visual support to help the adults understand what the staff are saying, *e.g. use gestures such as pointing to objects while speaking*					
37. encourage socialisation amongst adults, *e.g. approach adults and encourage them to join in during an activity*					
38. support the use of alternative communication systems provided to the adults, *e.g. sign language, communication boards, devices or schedules**					

* ☐Not applicable, no systems have been implemented

Section D: Current availability of resources and support for adults and staff

39. Are Speech and Language Therapy services and support currently available to the adults and staff?

Yes	No

If so, please describe these services including whom they are provided by:

_____

_____

40. Has any of the staff received formal or informal training regarding how to communicate with the adults or improve their communication skills?

Yes	No

If so, please describe:

Name of training: _____

Date: _____

Duration: _____

Name of service provider: _____

41. Are any communication resources currently available to the adults or staff in your facility? (These resources may include paper-based symbols, charts, visual schedules, communication boards or electronic communication devices.)

Yes	No

If so, please describe the resource and state who it was made by or acquired from

Resource description:	Made by/acquired from:

42. To what extent do you feel there is a need for professional development training to enable the staff in your facility to support communication of adults with intellectual disabilities? Please tick the appropriate box.

0 = no need	1 = little need	2 = some need	3 = extensive need

43. Please think about the following health and support needs for all the adults in your facility. Please rank them in order from the most to the least important:

1. Medication
2. Behaviour support needs
3. Communication support needs
4. Mental health needs
5. Mobility support needs

Most important: _____

_____

_____

_____

Least important: _____

Do you have any further comments or is there anything you feel is important for us to know or consider?

_____

_____

_____

_____

I may want to follow up on some of your answers. If you are happy for me to do so, please provide your contact details below:

Name: _____

Email: _____

Telephone number: _____

Thank you for your participation

Appendix D

Evaluation form for the questionnaire for expert panel review

Communication needs and opportunities of adults with intellectual disability and care staff in residential facilities ***questionnaire***

Expert feedback

Thank you for your willingness to assist with the evaluation of this questionnaire. Please complete your personal information below, and see further instructions.

Personal Information:

Please complete.

Name	
Profession	
Years of experience of working with adults (aged 18 and above)	
Years of experience of working with adults with intellectual disability (ID)	
Years of experience of working with adults with ID in residential facilities	

Aim of the evaluation

The attached questionnaire is intended to be sent to managers of residential facilities for adults with ID. They will be recruited from the Western Cape Province. All facility managers in the Western Cape will be invited to participate. They will complete the questionnaire themselves or can choose to delegate the completion of the questionnaire to a member of staff whom they feel is best able to answer the questions. The questionnaire will be completed in English. Your input is intended to assist me in ensuring that the questionnaire is complete, accurate and appropriate.

The questionnaire is based on a variety of existing materials from Sutherland et al. (2014), McKenzie, McConkey and Adnams (2014) and McCarthy et al. (1998)

The questionnaire asks about the following domains:

Domain	***Question number***
Background Information on facility and adults with ID	1 - 8
Communication skills and related skills of adults with ID	9 - 31
Communication skills of care staff working directly with adults with intellectual disability	32 - 38
Current availability of resources and support for adults and staff	39 - 43

Please use a pen to make written notes on the hard copy of the questionnaire. Alternatively, you may use the 'track changes' and/or 'comments' function in word to suggest changes or provide feedback.

Please provide input on the following

1. Please indicate if anything needs to be added on an item.
2. Please indicate if any items should be excluded (not appropriate).
3. Please indicate if any items are unclear.
4. Please suggest changes to items in order for all items to be appropriate to the context and participants.
   Please also comment in general on the following:

Length:
Formatting:
Any other comments:

Thank you for your valuable input!

Appendix E

Statement from Language Editor

Called to edit

Document title: Communication skills, resources and needs of adults with intellectual disability in residential facilities in the western cape and their support staff: A descriptive study.

Author: Alice Howes

Date Issued: 2019-10-25

This document certifies that the manuscript mentioned above has been language edited. The language editing includes spelling, grammar, overall style, referencing and punctuation. Called to edit does not take any responsibility for the research content and did not alter the intention of the author. This document ensures that the manuscript should be linguistically correct and edited for publication. It should be noted that all suggestions of Called to edit, was made in track change. Thus the author has the power to accept or reject all suggestions. Called to edit can thus not take responsibility for what the author choices to accept and reject.

For any further inquiry about this document do not hesitate to email: calledtoedit@gmail.com

Signature