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# Occupational therapy services for children with Autism Spectrum Disorder on the primary healthcare platform

# ABSTRACT

**Introduction:** The diagnosis of Autism Spectrum Disorder (ASD) is complex. In a low middle income country, like South Africa, early recognition of ASD rarely occurs on the primary health care (PHC) platform. To mitigate late diagnosis of ASD, which has a poorer prognosis, the purpose of this study was to identify the knowledge and clinical competencies required by inexperienced occupational therapists to improve early detection of and service delivery for children with ASD at the PHC level.

**Methods:** A descriptive qualitative design explored the perceptions of occupational therapy experts as to the required knowledge and clinical competencies necessary for inexperienced occupational therapists to deliver services to children with ASD on the PHC platform. Thematic inductive analysis was used to analyse the data.

**Findings:** Two themes emerged: Theme one: the perceived critical knowledge for early identification, assessment and treatment of children with ASD. Theme two: the clinical competencies required for assessment and effective treatment of children with ASD on the PHC level.

**Conclusion:** This study identified the perceived knowledge and clinical competencies needed to improve early identification and service community-based delivery for children with ASD on the PHC platform by early career occupational therapists.

# IMPLICATIONS FOR PRACTICE

- This study provides critical knowledge and clinical competencies to occupational therapists to facilitate effective therapeutic services to children with ASD on the PHC platform.
- The study identified appropriate screening, assessment and intervention that could assist occupational therapy service planners to reduce the gap of service delivery for children with ASD within the concept of UHC provision on a community-based level in SA.
- Faculty at tertiary educational institutions may utilise the findings in order to adapt curriculums to better prepare inexperienced occupational therapists with working with children with ASD on the community-based level.

### INTRODUCTION

Healthcare in South Africa is provided by two inequitable health care delivery systems, namely an under-resourced public healthcare system which provides for 73% of the population, and a well-resourced private sector which provides for the other 27%<sup>1</sup>. In November 2020, the government announced a 10-year timetable for the phased introduction of universal health coverage (UHC), funded by a National Health Insurance (NHI). These health care reforms aim to unify these two disparate health sectors following the principles as set out in the National Health Act [61 of 2003] Guide 3<sup>rd</sup> Edition<sup>2</sup>. The intention is to address the inequitable distribution of finances, large caseloads, poor infrastructure, and limited resources which have impacted on the public healthcare services' capacity to deal with amongst others, non-communicable diseases, including Autism Spectrum Disorder (ASD).

Autism Spectrum Disorder, considered the second most prevalent developmental disability in the world, has had a 30% increase since 2008<sup>3,4</sup>. Although ASD is a complex condition, individuals seldom require hospitalisation and in South Africa it is only when children fail to thrive, and/or their behaviour becomes increasingly problematic that they are referred to paediatric or psychiatric tertiary healthcare services for management. Even when they are referred within the public health sector (PHS) which approximately 73% of children utilise<sup>1</sup>, there are long waiting periods for specialist services and some children cannot access these centralised facilities due to high transport costs<sup>2</sup>. These factors contribute to an estimated 30% of South African children with ASD not being able to benefit from appropriate health care required to address the wide range of difficulties influencing their development, health and wellbeing<sup>5,6</sup>.

Early identification and treatment of children with ASD<sup>5</sup> is recognised as critical in improving and managing this condition<sup>7,8,9</sup>. Therefore, due to the chronic nature of ASD, children should be managed on the PHC platform. Early identification requires effective early screening to identify at-risk individuals at a PHC level, and once the diagnosis of ASD and medical management has been confirmed, treatment can be offered near the children's homes within the community setting<sup>7</sup>. In preparation for the introduction of UHC (funded by the NHI), opportunities now exist that such services for children diagnosed with ASD with the provision of rehabilitative services such as occupational therapy can be offered at the PHC level. However, health care workers, working on the PHC platform in South Africa are currently reported to feel ill-equipped in early treatment and identification of children with ASD<sup>7,8</sup>.

All children with ASD would benefit from occupational therapy to enable successful and age-appropriate performance in their daily occupations as well as positive engagement with their environment and society<sup>3,10,11</sup>. Such services at a PHC level in South Africa are likely to be delivered by inexperienced occupational therapists completing their community service year<sup>12</sup> (a year completed immediately after qualification as a requirement to obtain licensure as an independent practitioner<sup>12</sup>). There is a lack of research on occupational therapy service delivery for children with ASD, especially in PHC-based facilities in low to middle-income countries (LMIC)<sup>13</sup>. This has resulted in a limited understanding of the skills occupational therapists need to be able to identify children at risk of ASD and to provide early intervention once diagnosed<sup>13</sup>.

Therefore, this study aimed to explore the perceptions of expert occupational therapists, based on their experiences with children with ASD in clinical practice, as to the knowledge and clinical competencies inexperienced occupational therapists require to deliver essential services to children with ASD between ages of 2-6 years on the public PHC platform.

#### **Literature Review**

The 2021 Global Prevalence of Autism study indicated that, worldwide, approximately 52 million people have ASD<sup>14,15</sup>. The average global prevalence is just under 1%, affecting 1 out of 132 children aged 3-10 years<sup>15</sup> with 90% of people

with ASD reported to reside in LMIC<sup>14,16,17</sup>. South Africa has a reported higher than global prevalence with 1 in every 110 children (0-18 years) affected<sup>18</sup> thus placing a greater need on the healthcare system to provide relevant and appropriate services to individuals diagnosed with ASD<sup>18,19</sup>.

The symptoms of ASD are typically noted at 18 months of age and in well-resourced countries children are generally diagnosed between the ages of 3 and 5 years old<sup>4,1</sup>. It has however, been suggested that many children in South Africa remain undiagnosed and untreated due to a lack of understanding of this complex disorder and a lack of intervention opportunities provided on the PHC platform by a multidisciplinary team (MDT)<sup>6,9</sup>. A scoping review by De Vries<sup>17</sup> found that in South Africa, children screened as having ASD typically waited approximately 18 months to obtain an appointment with a specialist in the PHC sector for diagnostic purposes. This is consistent with the conference report by Ruparelia et al.6, which indicated that in African countries late diagnosis of ASD was common and the condition is not easily identified until the symptoms negatively influence typical development and the child's quality of life.

Recommended treatment for ASD involves a MDT approach on an out-patient basis<sup>20</sup>. Multidisciplinary intervention, including occupational therapy, has over time been found to assist these children in engaging with their environment and in performing their daily activities as they develop<sup>21</sup>. Although occupational therapy is reported to be an essential service for children with ASD, limited research has been reported regarding the best practice in ASD diagnostic assessment<sup>22</sup>, although Rutherford et al.22 highlighted the importance of each MDT member completing a comprehensive assessment of a child with ASD using evidence-based clinical guidelines. These guidelines for ASD (developed in Scotland) recommend that the three following components be included: clinical history, clinical observation and a contextual assessment - either through observation or the administration of appropriate questionnaire/standardised assessment tools. While certain assessments have been regarded as valid and reliable globally, based on research; they have high cost implications, require training and are time consuming to administer which limits their feasibility as ASD specific tools on the PHC platform in South Africa<sup>17,23-25</sup>.

Kadar, Mcdonald and Lentin<sup>25</sup> reported that as a result nonspecific diagnostic standardised assessments and informal observations are commonly used to provide insight into the occupational profile and behaviour of children with ASD, particularly in occupational therapy<sup>22</sup>. Typically a detailed clinical history is completed first by interviewing caregivers or family members, in order to provide a holistic view of the child<sup>22</sup>. Due to time constraints within the PHC sector and lack of early diagnosis; many therapists utilise a diagnostic treatment approach<sup>6,26–28</sup> defined as concurrently providing therapeutic intervention while observing symptoms and signs and observational skills during the commencement of therapeutic interventions to facilitate identification of at risk ASD symptoms<sup>22</sup>.

The best evidence for effective intervention for young

children with ASD recommend the use of behavioural and developmental approaches<sup>11,29,30</sup>, while Vinen<sup>31</sup> indicated that the two most frequently described interventions in occupational therapy are sensory-based and playbased approaches. According to Moosa<sup>21</sup>, South African occupational therapists working in the private sector, most frequently use sensory based and motor relearning approaches. These include Ayres Sensory Integration<sup>®</sup> (ASI<sup>®</sup>) and Neurodevelopmental Therapy (NDT). Therapists in this study also reported sometimes using occupation based, developmental and behavioural frameworks.

In South Africa, family-centred and parent-based interventions are usually considered when providing therapeutic intervention for children with ASD due to the insufficient number of health professionals to meet care demands<sup>17,32</sup>. This is consistent with the international trend where parent-mediated intervention has become popular due to a lack of healthcare professionals, high costs and poor medical coverage; resulting in children being less likely to obtain the necessary therapist-mediated therapy. Thus, parent-mediated therapy, thought to be more cost-effective, focused on coaching parents is used<sup>33</sup>.

There is little agreement as to the most effective intervention for children with ASD; and most of these therapeutic interventions require post basic qualification. Some authors emphasise that confidence, knowledge and skill regarding dealing with a child with ASD comes from clinical experience and practice<sup>34</sup>. The majority of the therapists working on the PHC platform, particularly in South Africa, are inexperienced and often in the early stages of professional development<sup>12,20</sup>. Thus, their knowledge of the ASD as a condition and their ability to provide effective therapy is based on their undergraduate learning, and supervised clinical experience, with input from work supervisors and colleagues<sup>35,36</sup>. Many therapists also report challenges in extending their basic knowledge and clinical competences<sup>20,25,34,35</sup> in relation to dealing with a child with ASD and an urgency to determine the gaps in knowledge and clinical competencies that need to be filled has been identified.

### METHODS Research design

This study used a qualitative, cross-sectional, descriptive design, where the data were collected from key informant interviews. This design was appropriate as the data provided a contextual experience for the perceptions and experiences of expert occupational therapists who have worked with children with ASD in South Africa to provide a deep and thick description of perceived the knowledge and skills set required to assist inexperienced occupational therapists to deliver services to children with ASD within a community setting.

### Sampling

Purposive and snowball sampling was used to recruit occupational therapy experts who met the inclusion criteria of at least 10 years' experience in delivering services to children with ASD in a variety of service delivery settings - including non-PHC platforms. Consenting participants were chosen based on the assumption they would have acquired the knowledge and clinical reasoning as well as have mastered the clinical skills for delivering services to this population. Consistent with qualitative research sample size<sup>37</sup> a small sample of 12 individuals were interviewed.

# **Research procedure**

All the key informant interviews were conducted virtually by the first author through: Skype, Zoom or WhatsApp video platform as the data collection process occurred during the National Alert Level 4 and 5 lockdown period of the COVID-19 National Disaster Regulations<sup>38</sup>. Passwords and meeting links were provided to the participants individually and confidentiality was ensured by both the researcher and participant being in a private, undisturbed rooms. Participants were given the option to keep their cameras on or off, allowing for interviews to either be audio recorded and or video recorded. Semi-structured interviews which included open-ended questions with several probes to facilitate in-depth discussions, were used to collect the data<sup>39</sup>. Ethical clearance for the study was obtained from the Human Research Ethics Committee (HREC) (M190917), University of Witwatersrand. Twenty-five potential participants across South Africa were contacted telephonically, but only 18 met the inclusion criteria. Of these individuals 12 indicated their willingness to participate in the study and gave written consent to participate and for the interview (1 hour - 1 hour 30 minute) to be audio-taped.

Prior to the interview consenting participants completed a short online demographic questionnaire about personal characteristics, professional education, clinical experience and continued professional development pertinent to ASD.

Data saturation was achieved at the sixth interview as new information from interview seven onwards contributed less than 5% to the codes that had already been identified in the data analysis using the data saturation index<sup>40</sup>. An audit trail recorded all the steps and decisions that were made during the research process. The trustworthiness of the research was assured by applying the principles of credibility (peer debriefing, triangulation and member checking), transferability (thick description and purposeful sampling by using expert participants in different provinces and service delivery contexts to provide diversity), dependability and confirmability (code-recode strategy used as well as peer examination through audit trails and bracketing)<sup>41</sup>.

#### **Data Analysis**

Data from both the demographic questionnaire (Table I, page 21) and the interview (Tables II and III pages 22 and 23) were analysed descriptively. Thematic descriptive content analysis occurred once the verbatim transcriptions of the interviews were checked for accuracy against the audio recordings. Coding was used to develop and modify the themes using the following steps: familiarisation with the data by reading and re-reading the transcripts; colour coding categories through direct content analysis; generating initial codes and themes; development of a matrix to place the themes, categories, and codes; themes reviewed by the supervisors and revised. The transcriptions were also

# Table I: Demographics and experience of participants

Participant	Age range (years)	Pro- vince	Work place	Years in field OT	Years treating ASD	Postgraduate education	Continuous Professional Development
Pl	55+	WC	PP PrS	25+	15-20	MSc OT (WITS)	DIR®-FCD; DIR®/FloortimeTM; Certified in ASI® (SAISI); NDT; Talks and workshops in ASD
P2	36-45	G	PP	10-15	10-15	MSc Child Health and Development Fine Arts Hons	ASI® (SAISI) level 1,2,3; 2.; Autism Centred Education tutor; Makaton (course and tutor); TEACCH; ACE; Lecturer for the MSc in Child Health and Neurodevelopment; some years working at school for Autism
P3	36-45	G	PP PuS	15-20	15-20	MSc OT (WITS)	DIR®/FloortimeTM
P4	26-35	FS	PP	10-15	10-15	M OT (UFS)	Introductory module DIR®/ FloortimeTM, Talks and workshops in ASD; (Completing ESD certification); Certified in ASI® (SAISI)
Р5	36-45	G	PP	10-15	10-15	MSc OT (WITS)	Talks and workshops in ASD; Makaton; SI training; Therapeutic listening; Hands-on autism course
P6	36-45	L	PP	15-20	15-20	Masters in Early Childhood Intervention (UP)	SNAP training workshop; DIR®/ FloortimeTM level; Certified in ASI® (SAISI); NDT
P7	26-35	WC	PP	10-15	10-15	Masters in Early Childhood intervention (UP)	Talks and workshops in ASD; DIR®/ FloortimeTM; Certified in ASI® (SAISI)
P8	46-55	EC	PP	25+	15-20	None	DIR® approach; ABA approach; Certified in ASI® (SAISI)
P9	36-45	G	PP	10-15	10-15	M OT (UP)	SI (SAISI); Makaton
P10	36-45	G	PP	10-15	10-15	None	Talks and workshops in ASD; SI training
P11	46-55	KZN	PP	25+	10-15	None	School autism unit for some years; DIR®/FloortimeTM (ICDL - Expert level)
P12	55+	WC	PP SA	25+	> 25	M OT (US)	Certified in ASI® (SAISI); DIR®/ FloortimeTM (level4); Interactive Metronome; Tomatis Consultant (level 3); Therapeutic Listening Musgatova MNRI; PTSD reflexes; PECS

Key: OT = occupational therapy; WC = Western Cape; G = Gauteng; FS = Free State; L = Limpopo; EC = Eastern Cape; KZN = KwaZulu-Natal; PP = private practice, PrS = private schools, PuS = Public schools, **SA = School of Apraxia** 

provided to a co-coder, who was also performing her research in ASD, to eliminate bias. The credibility of inductive codes was determined by repetition across transcripts, strong emphasis, topic changes or specific phrases.

# FINDINGS

# Demographics

All twelve participants were female, and 50% were aged between 36-45 years of age. Participants from six of the nine provinces in South Africa were represented, although the most were from Gauteng (n=5). (See Table I, above). Seven participants had 10-15 years of working experience and clinical experience with children with ASD, in a range of 10 to 25 years.

Participants' post-graduate training occurred at five different universities (see Table I, above). All participants had completed additional training by attending CPD courses on children with ASD. These included Ayres Sensory Integration (ASI®)<sup>42</sup>, Neurodevelopmental therapy (NDT), Makaton signing<sup>43</sup>, Picture Exchange Communication system (PECS)<sup>44</sup>,

DIR<sup>®</sup>/Floortime<sup>TM45</sup> and Therapeutic Listening<sup>46</sup>. The most frequently attended were ASI<sup>®42</sup> (9=97.5%), followed by DIR<sup>®</sup>/ Floortime<sup>TM45</sup> (n=8; 66.7%).

Two themes emerged from the collective data from the 12 interviews, pertaining to how to assess and treat children with ASD: The first theme described the perceived knowledge required, while the second theme described the clinical competencies necessary to treat children with ASD on the PHC.

# Theme 1: Critical knowledge required for assessment and treatment of children with ASD on the PHC platform

Theme 1 described the participants' perceptions of the Critical Knowledge for assessment and treatment of children with ASD on the PHC platform (Table II, page 22). The essential features of this theme described the perceived critical knowledge inexperienced therapists needed to understand ASD by referring to diagnostic criteria and presenting symptoms as well as 'red flags' and

#### Table II: Theme 1: Critical knowledge required for assessment and treatment of children with ASD on the PHC platform

Theme I	Categories	Subcategories	Codes	
Critical knowledge for assessment and intervention of children with ASD on the PHC platform		Diagnostic criteria	DSM-V: Diagnostic criteria and symptoms	
			Struggles with social connectedness and living own world	
			Communication, behavioural and sensory processing difficulties	
	Understanding ASD	'Red Flags'	Physical flags: motor control and praxis difficulties, lack body awareness, hyper-mobility joints.	
			Psychosocial flags: communication skills, sensory processing, struggles to relate and engage.	
			Challenging behavioural flags: restricted, routinised and repetitive behaviours; meltdowns; inappropriate behaviours.	
			Occupational dysfunction flags-: play difficulties; ADL difficulties; social participation difficulties.	
		Treatment considerations for the primary platform	Referral pathways	
	Understanding		MDT involvement	
	factors for ASD		Parent-child relationship	
			Cultural influence and impact on the intervention; stigmatisation and assumptions; accept and respect beliefs	

understanding intervention factors to be considered on the primary platform.

# Critical knowledge for assessment of children with ASD on the PHC platform

All participants (N=12) emphasised the importance of understanding the diagnostic criteria for ASD in terms of clinical and behavioural presentation. This would allow for early recognition of ASD, and ultimately timely intervention and effective communication about the diagnosis with other healthcare practitioners and caregivers.

"...first of all the signs and symptoms, so they need to understand what is Autistic Spectrum Disorder ..." [P1]

"DSM V and actually go through the criteria with them ... because that is clinically what we should use when we deciding whether a child is on the spectrum or not" [P5].

"...I think a vital competency is to be able to screen and identify very early in childhood what would be presenting signs or characteristics that they need to look out for [in children with ASD] ..." [P4]

# The majority of the participants utilised their understanding of the diagnostic criteria to form individualised definitions of what the inexperienced therapists should consider:

"[ASD] Is a child whose communication interaction is ... affected in such a way, also that they struggle to engage with their environment ...; engage with people around them, engage with activities and yes; with sometimes some behaviour that is out of sync. That is not normal typical behaviour for children ..." [P8]

"ASD is a neuro-biological challenge, a child has a really tough time organising or processing their world ... "[P1] "So, they really struggle with that social connectedness with other people. They are often in their own little world ...letting people into their world or them joining your world is very difficult." [P3]

Participants viewed some 'foundational' knowledge as 'red flags' to guide inexperienced occupational therapists in screening (physical, psychosocial, challenging behaviours and occupational dysfunction) through understanding the 'critical signs and symptoms' with which children with ASD may present. Most participants highlighted the observation of physical features and identified motor control and praxis difficulties as critical. They stressed children with ASD have difficulty with their body awareness as well as their difficulty with proprioception, visual-spatial challenges and tip-toe walking:

"...ASD there is very often motor control issues as well. We know from our occupational therapy perspective that many of these children have praxis difficulties, dyspraxia ..." [P10]

"...they are awkward, we know they are very clumsy, we know that their core control is extremely, extremely bad ..." [P7]

All participants believed the psychosocial symptoms to be the earliest identifying sign in young children for ASD, particularly communication skills. This includes non-verbal and verbal communication such as pre-linguistic and linguistic skills, specifically limited eye contact, joint attention and relating and engaging with others in their environment.

"...social interaction; not communicating; not giving eye contact, not being able to communicate appropriately, for that child's age, with a person." [P9]

Sensory processing difficulties were highlighted although this is not included as a DSM-V<sup>3</sup> criterion. All participants indicated that in their experience, children with ASD have sensory processing difficulties, particularly with their sensory modulation and therefore this should be considered an identifying feature:

Table III: Theme 2: Clinical competencies required for the assessment and treatment of children with ASD on the	РНС
platform	

Themes	Categories Subcategories		Codes	
Clinical competencies for assessment and treatment of children with ASD	Layered Assessment process	Tools to scroop	Red flag identification	
		TOOIS to screen	ASD specific screening tools	
		Non-Standardised assessment	Informal observation of milestones and occupational performance	
			Informal observation sensory modulation and behaviours	
			Parent interaction	
		Assessments	Non-ASD specific assessment	
	Families as partners	Parents and caregivers used	Educate and empower parents/caregivers and ensure a support system	
			Collaborate with parents/caregivers	
		process	Coach parents/caregivers	
	Child-centred practice therapeutic intervention	Goals/outcomes	Functional and occupation-based: simple, realistic and adaptable	
		Types of intervention	Sensory-based, Developmental, Behavioural	
			Other interventions	
on the PHC		Therapeutic use of self	Building trust, wait, watch and wonder	
platform			Be aware of body positioning, appearance and movement	
			Limit communication and utilise your voice and facial features	
		Occupational therapy principles	Follow child's lead -join child in their world	
			Regulate and modulate child; skill development in sensory appropriate environment; Uncluttered, small, structured	
			Start on child's developmental level - expand play in their interest	
			Intentional and constructive communication and social participation	
			Use behaviour	
			Provide therapy techniques appropriate culture and health literacy	

"...[a child with] ASD has a lot of sensory issues. Whether it's stronger towards the modulation side or stronger towards the praxis side ..." [P10]

The third red flag to emerge was the challenging behaviours that often occur with children with ASD. Inappropriate or atypical behaviours were viewed by participants as behaviours that were not age-appropriate to the child:

"It is about looking at the signs, what you are seeing in terms of relating; communicating, repetitive behaviours and restrictive interests ..." [P1]

""...when you see the poor language skills in combination with the lack of joint attention behaviours that becomes a huge red flag. So that is one for me and then restricted and repetitive behaviours ..." [P4]

Participants identified 'meltdowns' that occur as a result of sensory processing difficulties, which are a defining feature of ASD:

"So that if they were screaming, head banging, poor sleep, biting, yes there are processing problems which might be meltdowns if they cannot react very well to their environment." [P8]

The final red flag to emerge in identifying children with ASD was occupational dysfunction

"ASD is a syndrome that impacts a child's ability to act appropriately according to their age, in their play, in their social interaction, in their activities of daily living and in their scholastic environment ..." [P9]

# Critical knowledge for the treatment of children with ASD on the PHC platform

Knowledge critical to understanding the provision of occupational therapy services for treatment for children with ASD on the primary platform is awareness of referral pathways. This indicated the need for the role of occupational therapists to be aware of the public health system specialist and other multidisciplinary services which can be accessed for diagnosis and other supportive needs:

"I always feel very strongly that as OTs, you know, we very often refer a child with any deficits to a specific specialist or a doctor for a diagnosis, and you know that makes a big difference in terms of school placement or in terms of medication ...[PI0]

The knowledge of MDT involvement emerged as critical due to the complex nature of the condition, which results in understanding MDT interventions for relationships to be built with other healthcare professionals such as speech therapists and NDT physiotherapists to ensure improved service delivery for children with ASD:

"...so, I work very closely with our speech therapist. So, building those multidisciplinary relationships is very important." [P3] The parent-child relationship is important to understand in ASD, especially when providing early intervention and therapeutic services [on the PHC platform]:

"...establishing your relationship with parents and child, and that will be the starting point of your assessment.... .use your clinical reasoning there and see what the parents are doing and how they're handling the situation ..." [P9]

Finally, knowledge about the cultural influences on ASD and the impact they may have on intervention was perceived as important by the participants. Knowing, accepting and respecting beliefs was seen as essential to service provision for children with ASD. One also needs to understand the stigmatisation of the child and the family around the disorder, along with the assumptions that people in the community may have regarding the diagnosis:

"...I thought it was culturally appropriate for this child to eat with his hands... but for the family, they actually wanted to have him to sit with them and eat with a knife and fork." [P6]

# Theme 2: Clinical competencies required for the assessment and treatment of children with ASD on the PHC platform

Theme 2 described the participants' perceptions of the Clinical Competencies required for the assessment and treatment of children with ASD on the PHC platform (Table III p23). Participants highlighted the skills required for a layered assessment process and the importance of parent-mediated therapy and involvement of family members. Child-centred practice with emphasis on treatment goals, interventions and principles was emphasised.

# Clinical Competencies for assessment of children with ASD on the PHC

Participants explained what they perceived to be the layered process involved in the assessment of these children which needs to be followed by inexperienced occupational therapists for both higher functioning and lower functioning children.

The participants discussed the importance of tools to screen children with ASD particularly 'red flag' identification. Others suggested screening tools that identify psychosocial and behavioural difficulties including information obtained from the parents:

"I think early intervention screening would already help a lot because you can already start engaging at least [with the] behaviour because [that is] the biggest issue that the parents come and see us, is the behaviour." **[P8]** 

"... just include whatever background information I can get from the parents or the caregivers. In my practice I would do a sensory profile, the toddler questionnaire or the normal sensory profile ..., gross developmental milestones ..."[P10]

"...[initial interaction with parents] during intake [session] you're asking questions and when some of those red flags

come up: the language and they're difficult to be around, those kind of things ....." [P11]

Few participants suggested using ASD specific tools designed to screen children with ASD, and some suggested using a 'checklist' such as the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)<sup>47</sup>: as well as

"The Childhood Autism Rating Scale(CARS-2)<sup>48</sup> is also a really nice little tool that we can use ..."[P5]

Many participants reported using non standardised assessment over two or three sessions would be more beneficial than a specific assessment performed on a child who has been diagnosed with ASD:

"Our Autistic kids do not assess well at all and in general in our practice when we seeing a child under the age of three... where we assess them over two or three sessions ..." [P5]

Participants, who were experienced in children ASD, perceived that experiential learning is required but suggest these non-standardised assessments allow identification of the child's weaknesses and strengths and should include informal observation of the children's milestones and occupational performance, sensory modulation and behaviours in familiar contexts. Observation of the parent-child interaction in the assessment of a child should always be used to collaborate with their assessment findings:

"...So yes, I think informal occupation-based assessments generally work better with ASD kids because they don't follow verbal instructions. They don't sit down and do formal standardised tests. So, play-based and informal type of assessments definitely work better ..." [P4]

"...informal you know just observations... To see if they cope with movement input, see if they cope with tactile input, see how they react to various levels of maybe auditory stimulation, visual stimulation ..." [P10]

"I'll do observations in the classroom, observations on the playground around their social skills, around their postural control, around their fine motor skills, their ability to eat, to brush their teeth ..." [P3]

Participants reported assessment with non-ASD specific tools were also used to help assess the child depending on their age and level of functioning. These refer to either visual perceptual assessments, sensory profile or developmental assessments.

"I'd rather use something like a BEERY or a DTVP 2 or 3, because it's a lot shorter, and you can break it up into smaller bits if you needed to ..." [P3]

# Clinical Competencies for the treatment of children with ASD on the PHC platform

Participants viewed family partnership as important in the context of PHC with limited occupational therapy

services, by including the including parents and caregivers in the therapeutic process so they are part of the journey. Continuation of therapy at home due to limited time (session duration and sessions in a month) is essential. Parental support needs to be contextually and culturally appropriate:

".. I think it's really important to put them in touch with support groups and Autism South Africa's got lots of opportunities for that ..." [P5]

Educating and empowering the parents and caregivers by imparting knowledge about the treatment with children with ASD and attending to the support system for and needs of the parents, and caregivers' is important for the continuation of the therapeutic process at home:

"...I feel that, that is definitely where OTs can support the parents. They need to be empowered with information because if they understand why their child is doing something ..." [P2]

"...if parents understand what you're doing, they buy into it. Then you see better progress with the kids, for sure." [P7]

Occupational therapists need to collaborate with the parents and caregivers to ensure that the skills worked on in a therapy session with the child are based on a mutually decided goal and not just the outcome sought by the therapist. A proposed role of occupational therapists within the PHC is as a coach to the caregiver:

"...So, I ask them, what would make life just a little bit easier for you? And then from that I get things like, if he would stop pulling the dog's tail or if he would stop taking his clothes off... I see how I can get [to] that first goal for the parents while working on the developmental norms ..." [P6]

"...with therapy with autistic kids it's not about you being the great therapist, it's actually about you being the coach and helping parents ... [P11]

The importance of all treatment being child-centred was stressed since each child with ASD is unique and one treatment method cannot be applied to all children. Treatment should be planned and executed considering the uniqueness of the child and their needs:

"...So, I need to make a choice when I work with kids, what is the most relevant frame of reference or model to use with them [considering all the facts] ..." [P4]

Participants gave their views on the various approaches that inexperienced therapists should consider when engaging in therapeutic intervention. From their 'personal experience' and 'insight', four subcategories were identified:

• goals for occupational therapy to be congruent with the parents and child. All participants believed that the

goal/outcome should be occupation-based so that the focus of the child's function and not limitations could be identified. Goals should be simple, realistic and adaptable. Many participants reported that challenging behaviours occur when you expect the child to perform tasks that are too complex since they become overstimulated or overwhelmed.

"... taking that step back and asking them 'what are your goals, what are your ideals?" **[P5]** 

"Of goals; I think it is to keep it at least functional. Yes, all our goals must be functional anyway maybe simple..... what I do in therapy is that it should carry over at home." [P8]

"So, my goals change depending on the child on that day and what they need on that day....It's much smaller steps... much, yes....so very, very smaller goals because otherwise they get very discouraged" [P6]

Most participants highlighted that to ensure that 'buy in' and 'carry over' occur within the PHC platform approach, the goal must be not only beneficial for the child but for the family as well.

"...goals that are important to the family and to the child ..." [P5]

 types of intervention that could be provided and the foundational principles these experts use to treat children with ASD. The main intervention types used to treat children with ASD were sensory-based and developmental frames of reference:

" I think first and utmost for me myself in the practice, I think I wouldn't be able, and I don't think I will be willing to – treat any ASD children if I didn't have my SI background ..." [P10]

"The main tools, I suppose I would use with DIR is getting to their level ..." [P9]

Some participants reported the 'behavioural' interventions as being useful, especially Applied Behavioural Analysis (ABA) intervention, while others disagreed with utilising behavioural interventions within their practice:

"I think it's got a place for children but generally I don't like ABA for very young kiddies, I like it for my kids that are plateauing in OT ..." [P5]

- Other interventions used with children with ASD included communication interventions such as AAC and PECS. Feeding and brain balance programmes were also highlighted as interventions used with certain children with ASD but these interventions are not effective with all types of children with ASD. This was dependent on their needs and their therapeutic goals:
  - "...And then obviously things to get some sort of

communication so... or using the Pecs." [P7]

"....[if there is a] feeding difficulty specifically with all the age groups then I'll do the SOS feeding approach ..." [P5]

• Participants described specific principles for enhancing therapeutic use of self to engage a child effectively in sessions. These included:

Building trust was seen as an important factor in therapy sessions as many participants perceived that, children with ASD struggle to engage without trust due to their circumstances and experiences of the outside world:

"Yeah. I think I've learnt to use myself in a more therapeutic manner...So being able to modulate my response to a child's actions ..." [P3]

"...and I'd really wanna try and build trust because especially our kids in [the] community, they've been exposed to adults in their lives that are probably smacking, hitting, grabbing, pulling, shoving [to try to manage their atypical behaviour], ..." [P5]

Being aware of the child's body positioning, appearance and movement was an important element of the therapeutic use of self when approaching a child with ASD:

"It's using your body in a way that's going to encourage a child to engage with you or to do an activity...And allowing them into your space, or allowing yourself not to go into their space. So, reading the child appropriately, and using your body as; and all your actions that you do ..." [P3]

"Also, not wearing bright scrubs, kids respond to the colours that you are wearing, nail varnish, rings, long earrings, bangles that click." [P2]

Also, the effect that one's voice and communication can either limit or facilitate a child with ASD's engagement, with particular focus on tone of voice and facial expressions:

'It's using your voice in a way that's going to engage them again and again. Like I said, not too loud, not too soft, not too squeaky, not too deep, depending on what the child is needing ..." [P3]

"...at the beginning, just use the sounds and then later it would be "throw, throw" and then it would start being like the action word that you would use." [P7]

Participants also highlighted providing enough time to respond to an action, gesture or verbalisation. Be patient with children with ASD so they do not become overwhelmed.

"...the whole wait, watch and wonder thing is something that sits well with our core ethos ..." [P4]

· Participants reported using occupational therapy

principles or specific guidelines for therapy sessions that related to appropriate activity requirements, very specific presentation and handling principles, as well as considerations of the treatment context, including environment. In facilitating engagement and participation in the therapeutic activity, as participants considered these children generally live in their own world or space which provides them with comfort and follow their lead:

'follow the child's lead by joining them in their world': "... entering into [their space with] what they are interested in, helps them to regulate, stay calm and build-up a bit of trust ..." [P1]

Participants also believed that the child first need to be regulated and modulated using a sensory appropriate environment through sensory modulation techniques or a sensory diet before attempting to perform any activity or task:

"...start sessions, in a cloud, in a hammock; ...and then I would try and use the vestibular and proprioception [sensory modulation techniques] to try and just regulate the system bit before we even start actually participating in a game." [P9]

"first, the child needs to be regulated, calm and share an interest." [P1]

All participants indicated the environment being structured - an uncluttered small room with only having toys that are necessary for the session to reduce distractions. The same room should be used to provide familiarity to allow the child to feel safe. Furthermore, limited visual distraction, smells and sounds within the therapy environment need attention to ensure that the child does not become preoccupied or get overstimulated by visual input, as visual input is generally a seeking sense for children with ASD:

"... I always bring them into this small room, this room is my like assessment room. I mean you can see it is quite uncluttered and we got neutral colours, all blues ..." [P1]

"...being aware of your own smells and the smells in the environment and how that can affect the child is important as well. And then any sounds in the environment, so white noise, may be distracting to the child, so fans going, if you've got a fridge or a computer in the room, that can have a low-frequency buzz that may affect certain children. Your lighting is important, .... normal fluorescent globes spin at a certain frequency that children on the spectrum, people on the spectrum or sensitive people can hear... So, it will certainly affect their life and their response in your session and everything ..." [P2]

Participants highlighted starting on the child's developmental level and expand on their play by building on their interest using intentional and constructive communication and social participation. Include opportunities for pre-linguistic and linguistic skills, facilitate eye contact, joint attention and social engagement:

"...is working along these developmental levels of relating and communicating..." [P6]

"...it's almost like gentle playful obstruction that we do with these kids, so I think it's just changing the play with what they're doing and trying to get another level of play within that play. So just... yes, expanding it." [P9]

"...can they have shared and joint attention and then can we start having circles of communication." [P5]

Using the child's repetitive behaviour and restricted interests to build the trust needed for interaction to occur and utilising their interest or seeking behaviour to facilitate their engagement: Atypical behaviours should only be treated if they are causing dysfunction and not interrupting the child's engagement or causing harm:

"Now one could see, he was running and touching the poles, he was running back and forth, he was sliding up and down, he loves movement. So, I am going to use his preferred activities, his interests even if they are repetitive because they are my starting point ..." [PI]

Provide therapy techniques appropriate to culture and knowledge when dealing with PHC services in South Africa.

"...But I can't see that the way that I treat will be changed by the family's cultural beliefs, and I think that's something that we are very lucky with in OT ..." [P10]

# DISCUSSION

The study sample comprised 12 expert occupational therapists with 10 or more years of experience in dealing with children with ASD who were considered to be more than competent to provide the rich data for this study. Due to the limited number of occupational therapists with expertise in the specific context of this study namely the public sector, occupational therapists who worked in other sectors of practice with the same patient cohort were recruited to participate. Thus, the data included their perceptions of the importance of aspects from their own current practice in relation to knowledge and clinical competencies required for occupational therapy services on the PHC platform.

# Critical knowledge required for assessment and treatment of children with ASD on the PHC platform

As suggested by Rosenbaum and Gabrielsen<sup>49</sup> during assessments occupational therapy experts agreed that the recognition of the diagnostic criteria stated in the DSM-V, which support the 'red flags identifiers', is of utmost importance in identifying and understanding ASD<sup>49</sup>. These include challenging behaviours (restricted, routinised and repetitive behaviours; meltdowns and inappropriate behaviours)<sup>3,11</sup>; psychosocial difficulties (non-verbal communication)<sup>3,49</sup> and verbal and physical components

(poor motor control and praxis problems)<sup>3,50</sup> associated with ASD<sup>3,11,49,50</sup>. Although sensory processing/sensory modulation were viewed as at-risk symptoms for ASD, this 'red flag identifier' is not recognised within the DSM-V criteria<sup>3</sup> despite support in the literature indicating this as a prominent feature in children withASD<sup>25,35</sup>. Most participants also proposed that occupational dysfunction (play, ADL and social participation) is a significant factor in identifying children withASD<sup>3</sup>, although this feature was not consistently recognised in this study. This is of concern, as occupational performance should be key component of occupational therapy practice for young children with ASD<sup>51</sup>

Critical knowledge when considering treatment of children with ASD in PHC, identified by expert occupational therapists concurs with the study by Atun-Einy & Ben-Sasson<sup>20</sup> indicating the benefits of MDT and caregiver involvement. The findings align with literature indicating that children with ASD are best treated within an MDT and family collaborative setting<sup>20</sup>. Therefore, understanding the referral pathways was identified as critical for inexperienced therapists to understand and provide effective services to children with ASD<sup>9,20</sup>. A limiting factor in this study is that the majority of the participants were not working in the PHC and were therefore unable to provide much insight on referral pathways in this sector<sup>20</sup>.

# Clinical competencies required for assessment and treatment of children with ASD on the PHC platform

For assessment of children with ASD in PHC, the participants recommended that inexperienced occupational therapists perform - at a minimum - a comprehensive parent interview along with an informal observation and, if at all possible, a non-ASD specific assessment to determine the child's strengths and weaknesses. This was considered a good guideline<sup>22</sup> and crucial for an assessment in ASD, as the best clinical practice assessments have not been identified for this population in South Africa<sup>22</sup>. Although some non-ASD specific assessments were identified as useful by the participants in this study, most participants disagreed with Baxter et al<sup>15</sup> and Kadar, Mcdonald and Lentin<sup>25</sup> on the usefulness of standardised assessments. Rather the expert occupational therapists indicated that due to limited time available informal observations and the use of checklist for identifying ASD symptoms<sup>22</sup> be considered. Formal screening assessments such as the MCHAT<sup>47</sup> CARS<sup>48</sup>, or Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)<sup>52</sup> are available with varying reports on their utility. Only the MCHAT, which is freely available and is in the process of being translated into some local South African languages<sup>53</sup>, is likely to be used at a PHC level. The observations and screening should be triangulated with parent interviews would provide more of a holistic picture into children with ASD abilities than screening assessment scores on the PHC platform<sup>6,17,27</sup>.

The findings of this study reiterated the findings of Naidoo, Van Wyk and Joubert<sup>54</sup>, namely that the role of occupational therapists needs to be adjusted within the re-engineering of the PHC platform. Inexperienced therapists should align their services with the principles of PHC and UHC, to

improve services to and quality of life of children with ASD. Inexperienced occupational therapists should use more of a parent-mediated technique by coaching caregivers<sup>2</sup>. This view is consistent with other various literature<sup>17,32</sup> and agrees with the findings by Franz *et al.*<sup>32</sup>, that providing parents with education and techniques to manage their child is of more beneficial than providing a once-off therapeutic session.

Expert occupational therapists recommended that the parent-child relationship was influential in the therapeutic process when providing services to children on the PHC platform. Inexperienced therapists need to be aware of this to provide families with appropriate techniques and skills that are suitable to the family, context and culture as supported in literature<sup>33,55</sup>. These views supported reports by Pang *et al.*<sup>5</sup> that treatments for ASD on the PHC platform need to accommodate the cultural practices within South Africa's context to be effective and culturally appropriate.

The participants indicated that occupational therapists need to set goals and treatment outcomes to ensure therapeutic benefits within sessions<sup>33,55</sup>. Both goal setting and parent involvement were perceived as essential for treatment outcomes. However, the participants did highlight some goals that inexperienced occupational therapists can achieve during sessions - these should be simple, functional, measurable and easy enough for both the inexperienced therapist and parents/caregivers to identify and achieve practically. Patriquin, MacKenzie and Versnel<sup>56</sup> concurred with this finding that goals regarding the managing of challenging behaviours, occupation and psychosocial areas of development were essential but did not provide any specific goals for children with ASD. Despite the literature reporting that goal-setting was occupation-based and functional, expert occupational therapists within this study reported intervention to be predominantly focused on the underlying deficits and very few focused on the occupational performance deficits which could relate to developmental stage of the child<sup>11,21,34,49,55</sup>. It appears however that for younger children a predominantly bottom-up (sensorybased, developmental, behavioural) rather than top-down (occupation-based) intervention approach is suggested. The use of occupational performance and participation issues were prioritised for older children<sup>11,50</sup>.

Although the efficacy of intervention has been debated occupational experts proposed simple and foundational strategies that inexperienced occupational therapists are taught in undergraduate training<sup>57</sup> to utilise within treatment sessions. However, they agreed with Akhter, Mumtaz and Sagulain<sup>58</sup> that inexperienced therapists do not always have the underlying ability to integrate clinical competencies into practice on the PHC platform. This included the basic treatment principles, sensory stimulation (sensory-based), family-centred and developmental approaches, that can help therapists to facilitate play and caregiver engagement to promote childlead engagement gradually and sequentially<sup>29,30,32</sup>. This concurs with Vinen<sup>31</sup> and Moosa's<sup>21</sup> intervention findings within South Africa context. While behavioural approaches were discussed, the expert occupational therapists did not use the behavioural interventions often, as some had concerns regarding this type of intervention. Therefore, the findings of this study aligned

with those of Salomone *et al.*<sup>55</sup> but disagreed with evidence from other studies supporting behavioural intervention, which appears to be more widely used in developed rather than developing countries<sup>11,29,30</sup>. Other beneficial interventions found in the literature and mentioned by some participants in this study were communicative techniques and sound-based therapy<sup>59</sup>. These interventions typically require additional training and may not be plausible on the PHC platform nor are they recommended for inexperienced therapists<sup>56</sup>. Furthermore, the expert occupational therapists indicated that different interventions are more appropriate at different ages and phases of a child's development which is consistent with research<sup>60</sup>.

Fundamental occupational therapy treatment principles that perceived clinical competencies were identified by the expert occupational therapists. These principles were commonly applied within their sessions and were considered contextually appropriate on the PHC platform<sup>54</sup>. Some of these principles identified by the participants are basic occupational therapy principles that are routinely taught in undergraduate programmes. Limited literature discussed principles within a therapeutic session without requiring additional training; due to the various types of intervention, the principles differ within these interventions. Of the principles identified by the expert occupational therapists, only one of the principles is reported to be identified and agreed upon within the literature, namely the structuring of the environment which consistently influences a child's engagement<sup>11,29,30</sup>.

Expert occupational therapists highlighted the principle of therapeutic use of self as a clinical competency to use in establishing the therapeutic relationship with the child and caregivers. In addition, they recommended that factors such as being aware of one's own appearance and body position, the utilisation of their verbal and non-verbal communication, and providing time for a child with ASD to respond to the given task. No specific literature was found to collaborate or oppose these suggested therapeutic use of self-strategies; although general guidelines for all children were evident in the literature<sup>61</sup>.

Other foundational principles identified were largely influenced by Sensory Integration (SI)<sup>42</sup> and DIR®/Floortime<sup>TM45</sup> principles, including following the child's lead and joining the child in their world, starting on the child's developmental level and expanding on their play by building on their interest. The principle of regulating and modulating the child before skill development through a sensory-appropriate environment emanates from the SI and DIR® intervention types<sup>42,45</sup>. Although some principles are perceived to be plausible without additional training, particularly regarding body positioning and appearance, wait, watch and wonder and verbal and non-verbal strategies, it is important to acknowledge that some of these principles are rooted in DIR<sup>®</sup>/Floortime<sup>TM45</sup>. The principle which was not specifically identified through other interventions within the literature was the use of behaviour to help facilitate engagement in the sessions. Many participants in the study highlighted the inclusion of repetitive behaviours and restricted interests at the beginning of therapy in order to obtain engagement and interaction from the child.

The last foundational principle to emerge was providing therapy techniques that are appropriate to culture and knowledge. Literature by Wetherby<sup>26</sup> and Pang *et al.*<sup>5</sup> has identified cultural influences extensively. While there is a cognitive awareness of how culture can impact therapeutic intervention, many experts reported that their use of techniques did not always focus specifically on cultural appropriateness. This largely highlights the adaption required for occupation-based service provision rather than just using approaches and techniques alone. This was supported by James, Pizur-Barnekow and Schefkind<sup>36</sup>, who stressed the need for services and treatment for ASD to assist with cultural and linguistic diversity within South Africa.

It is suggested from this study that inexperienced occupational therapists required additional knowledge and education<sup>6</sup> to provide screening, assessment and intervention services to children with ASD on the PHC. Participants agreed with Juraszek *et al.*<sup>61</sup>, that improvements in the information content of the occupational therapy undergraduate degrees are required to facilitate improved services to children with ASD. However, while there has been a call for revision of the undergraduate curriculum on ASD, a lack of teaching time was confirmed by Naidoo, Van Wyk and Joubert<sup>54</sup> Furthermore, minimum standards of training for occupational therapists by HPCSA does not prescribe the inclusion of any specific health conditions but requires students to integrate and apply knowledge skills and attitudes to people of different ages<sup>61, 62</sup>.

# Limitations

This study had several limitations which may influence the findings and thus these need to be considered with care. Although the findings from this research study agreed with the literature, occupational therapy principles for treating children with ASD, the therapeutic use of self and treatment considerations on the PHC from this study were not identified in the literature. This study also acknowledged the limitations regarding population sampling and the method of obtaining data.

### CONCLUSION

Inexperienced occupational therapists are confronted with children with ASD on the PHC where they feel ill-equipped to provide therapeutic services to this population. To enhance inexperienced occupational therapists' ability to serve a population that will benefit from early detection, appropriate referrals and effective intervention; this study set out to explore the views and perceptions of expert occupational therapists working in private/public health or educational settings within South Africa, on the knowledge and clinical competencies required for inexperienced occupational therapists when working on the PHC platform to screen, identify, assess, and treat children aged 2-6 years with a diagnosis of ASD. The critical knowledge and clinical competencies which would enable services within the PHC platform was explored. Despite the scarcity of ASD-specific services on the PHC platform, possible assessment strategies that inexperienced therapists could utilise alongside screening tools, treatment strategies, intervention types and techniques; which could

facilitate confidence with dealing with children on the PHC platform were described. This study identified occupational therapy treatment principles and techniques in addition to the therapeutic use of self as important for inexperienced therapists. The findings acknowledged that there is a possible gap in knowledge and clinical competencies in undergraduate training, which was not unexpected as the undergraduate courses aim to provide fundamental knowledge and skill and not cover all clinical eventualities.

### **Conflict of interests**

No conflicts of interest declared by the authors.

# **Contribution of Authors**

Rikki Greenberg – postgraduate student who conceptualised and completed the research and contributed to the article. Pat de Witt and Marica Botha- supervisors and conceptualisation of the research project and peer review of analysis with contribution to the article

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