



Caregiver descriptions of joint activity routines with young children with autism spectrum disorder in South Africa

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Background: Coaching caregivers to deliver Naturalistic Developmental Behavioral Intervention (NDBI) strategies to their young child with autism spectrum disorder (ASD) could help address the provider capacity barrier in sub-Saharan Africa. However, the behavioral and developmental research that underpins NDBIs is overwhelmingly drawn from high resource settings. Therefore, our understanding of joint activity routines, including play and family routines in which NDBI strategies are embedded, may have limited applicability in low resource, culturally diverse environments. Important questions remain on how to adapt NDBIs to be relevant in the family lives in these settings. This study aimed to elicit descriptions of joint activity routines from caregivers of young children with ASD in South Africa, to understand whether an NDBI-informed caregiver coaching could ‘fit’ within the multicultural, multilingual South African context.

Methods: Four focus groups were conducted with 22 caregivers of young children with ASD who were recruited from the Western Cape Education Department autism waiting list. Data were analyzed through directed content analysis, which uses inductive methods to determine salient themes and subthemes. The predetermined initial coding classifications were based on joint activity routine categories of object-based play, sensory social routines, and family routines.

Results: Participants’ descriptions of caregiver-child interactions aligned with a-priori joint activity routine categories. During object-based play, caregivers engaged in turn-taking, taught developmental skills (for example cognitive, language, and fine motor skills), and participated in child-directed activities. During sensory social routines, caregivers described active, physical play, awareness of child affect, increased child expressive language, and willingness to engage with different play partners. During family routines, caregivers detailed child participation in mealtime and bath time.

Conclusions: These data suggest that South African caregivers of young children with ASD use joint activity routines to engage their children and teach them new skills, thus suggesting a degree of ‘fit’ between South African caregiver-child interactions and an NDBI-informed caregiver coaching approach. However, more information on family routines and which caregiver interacts with the young child with ASD during these routines would help tailor these interventions for low-resource African settings.

Keywords: Autism; autism spectrum disorder (ASD); South Africa; early intervention

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and restricted, repetitive patterns of behaviors or interests (1). People with ASD display a range of intellectual and language abilities, social communication skills, patterns of restricted interests and repetitive behaviors, and comorbid conditions. It is estimated that more than 52 million individuals (1 in 132) have ASD worldwide (2). However, there are regions in the world where no population-based prevalence studies have been conducted. For example, no prevalence studies have been conducted in South Africa, or anywhere else on the African continent. Additionally, there are few publications on ASD intervention on the African continent (3). Furthermore, few policies and systems of care exist to provide early detection and intervention for ASD in sub-Saharan Africa, where the number of children with developmental challenges has increased by 70% over the past three decades (2,4).

Although children can be diagnosed with ASD as early as 18–24 months (5), the median age of diagnosis in the United States (US) is four years eight months (6). Inequities in access to healthcare based on race and socioeconomic status contribute to this delay (6). Effects of health inequities are not limited to the US. In South Africa, a country marked by stark health-disparities (7), racial variations have been reported in expressive language abilities at time of diagnosis (8). Early detection and early intervention for ASD is critical because it can reduce the severity of ASD symptoms, and result in significant long-term improvements in language, social skills, cognitive abilities, and adaptive behaviors (9–12). In addition, it can decrease long-term costs of special education, and supported living and employment (13). Early intervention is in keeping with the United Nations Sustainable Development Goals, which include universal health coverage and access to quality care (14).

Naturalistic Developmental Behavioral Interventions (NDBIs) are a common set of empirically-supported approaches to early ASD intervention. NDBIs are derived from the principles of behavioral learning and developmental science, and target precursors of language development (15). Common features of NDBIs include the use of three-part contingencies, environmental arrangement, and child-initiated learning (15). The Early Start Denver Model (ESDM), one of the NDBIs, was the first empirically-validated comprehensive

intervention for toddlers with ASD (16). ESDM asserts that early developmental skills are best learned within meaningful social relationships, and that a lack of early social engagement is one of the main obstacles to learning in young children with ASD (16,17). Caregivers can incorporate NDBI-strategies into ongoing daily routines (15). The World Health Organization's Mental Health Gap Action Programme (mhGAP) strongly recommends caregiver education and skills training post-ASD diagnosis (18).

Joint activity routines, including play and family routines, are characterized by joint engagement and shared positive affect (19), and involve two or more partners joining together to carry out an activity (20). Object-based play includes a variety of toys, for example pushing a model car around a race track (21). Sensory social routines are social games which are marked by face-to-face interactions without an object, and reciprocal social behavior, for instance, tickle games (17). Family routines include activities of daily living, such as mealtime (22–24). Importantly, caregiver use of NDBI strategies during these joint activity routines promotes child joint attention and affective engagement, which predict language acquisition (25–27).

Currently, there is a dearth of behavioral and developmental research that examines the theoretical underpinning of NDBIs outside of high-income countries (28). This is a major gap because NDBIs take place in the context of play and daily routines and existing research is based on routines that have primarily been identified from high income settings. Research on child play has shown cross-cultural variation in objects used and play partners, with some cultures reporting limited playful interactions between children and adults (29–32). In societies where children are interdependent, young children may more often be guided in play and daily routines by older children than by their adult caregivers (33,34). Due to the importance of community and kinship systems in sub-Saharan Africa, many relatives tend to be involved in child-rearing (35). In addition, extended family and community members may be thrust into the role of primary caregiver as a necessity, due to parental death from communicable diseases, such as HIV/AIDS (36).

There is limited research describing joint activity routines in sub-Saharan Africa. To our knowledge, there are two publications on caregiver-child joint activity routines, both from South Africa (37,38). Using the Family Routines Inventory, Schlebusch and colleagues conducted a study with 180 families of young children with ASD aged three to eight years (37,39). The study found that families with

more predictable routines experienced greater quality of life than those with less predictable family routines. Commonly endorsed routines included parents reading stories to their children, and children completing morning routines, such as brushing their teeth. Family routines were assessed with an English, self-administered questionnaire developed in the US. Authors acknowledged limitations of this approach in a population with low literacy and significant language diversity (37). The second study reported on caregiver-child joint activity routines as part of translating the Autism Diagnostic Observation Schedule-2 (ADOS-2) into Afrikaans (38). Smith and colleagues conducted an ethnographic investigation of social interactions and activities in a community sample of 40 typically developing Coloured children aged 12 months to 19 years from low-middle socioeconomic backgrounds. While just over half of the caregivers reported that they interacted with their children daily, 38% reported engaging infrequently in caregiver-child interactions. Most read books and shared stories with their children. In addition, caregivers described pretend games, including imaginary 'house' games, and play with dolls. Sensory social routines most frequently endorsed by caregivers included hide and seek and chase games. Frequently endorsed play materials included jump ropes, balls, and cars. Certain ADOS-2 activities, such as the *Happy Birthday* task, were unfamiliar to participants. The authors suggested that this unfamiliarity was likely due to low socioeconomic status resulting in limited exposure, rather than true cultural differences (38). While the study conducted by Smith and colleagues provides a caregiver narrative of child play, social interaction, and social activities, these descriptions were from caregivers whose children do not have a known developmental disability. Differences in caregiver-child interactions have been documented in young children with ASD relative both to typically developing peers and children with developmental disabilities (40).

Given that NDBIs take place in the context of daily routines, where caregivers embed NDBI strategies to support their child social communication development (15), it is essential to understand the nature of joint activity routines that occur between caregivers and their young children with ASD when attempting to implement NDBIs in new settings. Important questions remain regarding how to adapt NDBIs so they are relevant to the family life of diverse cultural groups. Therefore, alongside efforts to implement NDBIs in community settings globally, we need to ensure that we understand the context in which caregiver-child dyadic

exchanges occur. This study aims to provide qualitative descriptions of caregiver-child joint activity routines from the perspectives of multicultural caregivers of young children with ASD in South Africa. These qualitative caregiver descriptions will provide a broader understanding of how an NDBI-informed caregiver coaching intervention could fit in the South African context.

Methods

Setting

This study was conducted in Cape Town, South Africa. Cape Town has a population of 3.75 million people from diverse racial, ethnic, and socioeconomic backgrounds (41). According to the World Bank, South Africa is the most unequal country in the world from an economic perspective (42). This severe economic inequality extends into the health sector (7). The Western Cape Province is relatively well-resourced in terms of healthcare (43,44). Despite this, access to ASD diagnostic and intervention services is extremely limited (4). In 2016 the Western Cape Education Department Provincial ASD waiting list for special school placement included the names of 940 children, 646 of whom were younger than seven years of age (45). South Africa, which has a population of over 50 million, has nine ASD-specific schools, the majority of which do not provide early ASD intervention services or support, given that mandatory school entry age is seven years. The majority of families of young children with ASD are seen in the public health care sector, once every 4–6 weeks by either an occupational or speech therapist for a 30-minute session (4,46).

Participants

Participants included 22 caregivers of young children with ASD, from various ethnic backgrounds in South Africa (see *Table 1*). Their children differed in their ASD intervention history. While each child had access to the low-intensity intervention offered by the Department of Health, some were not enrolled in services, while a few had received private therapy (e.g., applied behavior analysis or special education preschool). To our knowledge, none of the participants had prior exposure to an NDBI-informed caregiver coaching intervention. Study inclusion criteria were as follows: (I) primary caregiver of a child with a confirmed diagnosis of ASD between the ages of 24 and

Table 1 Caregiver demographics

Data collection method	Focus group discussions (n=4)
Number of total caregivers	22
Gender of caregiver, n [%]	
Male	4 [18]
Female	18 [82]
Race/ethnicity, n [%]	
Coloured [†]	10 [45]
Black African	8 [36]
White	2 [9]
Asian/Indian	2 [9]
Caregiver role, n [%]	
Father	4 [18]
Mother	16 [73]
Grandmother	2 [9]
Number of total children	18
Gender of child with ASD [‡] , n [%]	
Male	16 [89]
Female	2 [11]

[†], coloured is a South African term for individuals with mixed racial heritage; [‡], ASD: autism spectrum disorder.

59 months; (II) caregiver's place of residence no more than 1 hour from the University of Cape Town (UCT); and (III) ability to travel to UCT for a focus group. Recruitment was conducted via telephone using the Western Cape Education Department Provincial ASD waiting list for special school placement, utilizing convenience sampling.

Procedures

The study was approved by UCT Human Research Ethics Council (HREC) and the Duke Institutional Review Board (UCT HREC: 039/2015 Duke IRB protocol: Pro0006292). Participants signed informed consent prior to data collection, and four focus groups were conducted between June and July of 2015. Focus groups were co-facilitated by UCT faculty and a Duke University master's student. Focus group co-facilitators had experience working with young children with ASD and conducting focus groups. The focus group guide contained 32 open-ended questions (Supplementary file). The current study focused on the questions related

to caregiver-child play and daily routines. The length of the focus groups ranged from 1.5 to 3.5 hours. One focus group was conducted in isiZulu, the primary language of the participants, and translated into English. All other focus groups were conducted in English, with brief isiXhosa and Afrikaans phrases interspersed throughout.

Data analysis

Focus groups were video recorded, transcribed verbatim, and cross-checked by two members of the research team. Data were analyzed using directed content analysis, which uses existing knowledge to identify and define key concepts to categorize initial themes (47). This process includes two main steps: (I) coding transcripts with predetermined initial themes; and (II) identifying and analyzing data that cannot be coded to determine if this data represents a new idea/theme or a subcategory of an existing theme (47). This method of analysis allows researchers to validate or extend conceptual frameworks or theory. The predetermined initial coding classifications were based on ESDM joint activity routine categories of object-based play, sensory social routines, and family routines (24). This deductive analytic approach was used to determine whether joint activity routines 'fit' with descriptions of caregiver-child interactions and play provided by caregivers of young children with ASD in the South Africa. Two coders analyzed each individual quote, line by line, to identify themes and subthemes within the transcripts. Data were compiled into matrices to synthesize the information, using direct quotes from participants to describe the salient themes and subthemes. The themes and subthemes were finalized via an iterative coding process. Consensus occurred through regular sessions in which two coders reviewed themes, sub-themes, and associated quotes. Study rigor was ensured through peer debrief, reflective journaling, and checking transcription accuracy. Sub-themes, described below, such as 'dyadic interactions', emerged and represent the various dimensions within each larger theme.

Results

Participants' descriptions of caregiver-child interactions aligned with a-priori joint activity routine categories of: object-based play, sensory social routines, and family routines. Themes and their corresponding subthemes are presented in *Table 2* and discussed below.

Table 2 Summary of themes and subthemes

Themes	Subthemes
Object-based play	Dyadic interactions
	Caregiver incorporating learning into play
	Caregiver joining in play
Sensory social routines	Awareness of affect and social cues
	Variety of play participants
Family routines	Mealtime routines
	Bath time routines

Table 3 Caregiver examples of object-based play

Conventional	Symbolic
Child and caregiver put together 10-piece puzzles	Child turns Play-Doh into the shape of a dog, makes it bark, then gives Play-Doh to the caregiver and expects them to do the same
Child drives around toy cars and makes “vroom” sound as they move around	Child builds blocks into the shape of a gun and says, “pow, pow”
Child uses toy kitchen set to cook breakfast for his family and feeds them	Child and siblings sit on top of a blanket and use it to pretend to have a picnic together
Child color codes sticks by pushing them into polystyrene	Child and siblings get underneath a blanket and use it to pretend to go camping together

Object-based play

South African caregivers of young children with ASD described participating in object-based play with their children. Object-based play involves a child or caregiver using a toy or object in a conventional manner. An example of this type of play described by caregivers included building Legos or putting together puzzles. Object-based play may also involve more complex, symbolic play where ‘placeholders’ are used to represent things that are not physically present. For example, another caregiver described their child forming Play-Doh into the shape of a dog, then making barking sounds. *Table 3* lists caregiver examples of conventional and symbolic object-based play with their young child with ASD.

Three subthemes emerged under object-based play:

dyadic interactions, caregivers incorporating learning into play, and caregivers joining in play. Dyadic interactions included back-and-forth exchanges between caregiver and child while playing with objects. Caregivers reported incorporating various child learning opportunities into object-based play, where they taught academic and social communication skills. Caregivers also described following their child’s lead into preferred object-based play activities.

Dyadic interactions

Caregivers described turn-taking and back and forth exchanges during object-based imaginative play:

“He likes building Legos, so we play with the Legos and build together. We build different structures. He will give me the pieces and I will build, and I must give him the pieces and he will build.”

“He does a lot with imaginative play. We have this shop toy and he will either be the shopkeeper and I will be customer, or we will do the reverse. He involves his sister and his father. He has a kitchen set, so he will cook the food and ask me what I want for breakfast, and then he will make it and bring it and I will have to eat it and then I will have to make him something.”

One caregiver described how she incorporated information she learned in therapy sessions to create dyadic interactions during object-based play, that involved taking turns to place puzzle pieces:

“One thing I have learned that they teach us at the speech/ occupational therapy is that we must play games with him. You must always be the person playing with him. If he puts a puzzle piece in, then you also put a piece of puzzle in. It is my turn and his turn.”

Caregiver incorporating learning into play

Caregivers reported incorporating social communication and cognitive teaching opportunities into play by using toys, books and technological devices. One caregiver described using picture books to teach her child different animals. In addition, she notes non-verbal communication skills, including eye contact and pointing:

“He will always take a book because he knows there are pictures in his books. He will come and look at you, point at something, then look at you and say, “Sheep”. He will always look at you for confirmation that it is right.”

Another caregiver noted that working on puzzles with her son had helped him learn to count:

“He likes to play puzzles. You know the eight-piece puzzles?”

And the letters as well. Like the 1, 2, 3... he counts to 30. He can count. We buy the eight-piece puzzles for him and he likes to put them together."

Technology was also used by caregivers teach cognitive and language skills:

"I can hand him my phone, and he will go into his peace zone and watch and imitate what he hears. With him it is very much technology. It is media that is helping him. His awareness of how to speak, interact, colors, and puzzles. He learns like that. After he watches something, I give him a puzzle to do, and he is so fast with counting 1 to 10."

Caregiver joining in play

Caregivers described joining in play with their child during object-based play activities. In these instances, their child would initiate an activity and the caregiver would follow the child's lead. Caregivers noted that if the child initiated an activity, the child was more likely to stay engaged and allow the caregiver to be part of their play:

"If I see their interest moving one way, I try and jump on that. I will see one of the boys looking to do that, then I will get involved there for a moment and try to get him to interact with whatever it is. Whether it is placing puzzle pieces, or colored sticks being pushed into polystyrene to color code those."

The following quote describes how a caregiver followed her child's interest in toy cars and in so doing helped him vary his play, and play functionally with the toy:

"He loves cars. He used to just line them up. I tried to get him not to just line them up. I would go down and play with him and indicate that it is a car and it is driving. 'Vroom', with sound. 'Vroom'. He did not do anything. But one time he surprised me when he was playing alone with his cars. I hear the sound 'vroom!'. I am like 'Okay! Yes! The car! Drive like that! Vroom!'. Then I saw him drive it around [motions a circle with her hand] and turn and all that. So now he does not go straight to just lining them up."

The caregiver below discusses joining object-based play activities after her child asks her to participate:

"He will come and ask you to play. He likes to play with Play-Doh and making things. He will make a dog and, say 'how how' and then he will give you your Play-Doh to make your own dog."

Sensory social routines

In sensory social routines, two subthemes emerged including: caregiver awareness of child affect and social cues during sensory social games, and caregiver descriptions

of a variety of play participants children engaged with during sensory social routines. Caregivers recognized their child enjoyed sensory social activities, as their child shared positive affect with others during these interactions and indicated that they wanted the activity to continue. A variety of play participants interacted with children during these routines.

Awareness of affect and social cues

During sensory social routines, caregivers reported positive child emotions directed towards them, and child social communication attempts to request to continue activities. Children enjoyed tickling and other physical games, and caregivers recognized when their child was interested in them during these activities. In addition, they were aware of their child's attempts to continue a sensory social game and thought that this enjoyment may enhance child learning.

Below a caregiver describes changes in her child's level of interest, engagement and learning ability based on 'playful' social routines:

"I have noticed with my child that when I am playing with her, she is more confident. She gets more words out. When we are playing, I will say a word, she will say it. But when you are serious, she will not say the word. I think a nice way of teaching my child is through play. It is very beneficial. She learns more in playing than being serious, sitting at a table with the paper and pen. When you play, I think she gets more out of it."

Another caregiver discusses how their child expresses positive affect during social games:

"He jumps on my back, pulls me, and says 'power rangers'. I have to run around. The way I know he is having fun—he is laughing and smiling. Or he says, 'catch me', 'one more, one more', and I have to do it over and over."

The following caregiver explains how she knows her child is having a good time during social games:

"He laughs while kicking the ball. He knows the days for soccer: Saturday and Sundays. When he kicks it and slides you must clap for him and then he will say 'afa, afa' which means Bafana Bafana [The South African National Soccer Team]."

Variety of play participants

This sub-theme captures descriptions from caregivers of several types of play partners their children engage with during sensory social play activities. In object-based play, caregivers reported that they were their child's primary play partner. However, during sensory social routines, caregivers

described their children playing with other children in their community, and immediate and extended family members, such as siblings, grandparents, and uncles.

In the following quote, a caregiver describes her child having fun while playing with other children, exhibiting positive affect, and using social communication skills:

“He is even playing with other children. They are playing outside and jumping and singing. He knows how to sing, and he knows he likes to sing. You can hear that he is singing those words. The words that he knows. He plays with other children with the ball. He is excited if he sees that ball. If he wants to play ball, he comes to you and says [in isiXhosa] ‘khaba’. Khaba is just kick, kick.”

This caregiver discusses how her son interacts with his cousins and how growing up together has helped them understand and support him:

“He is great at playing with his cousins. They have been good support from the beginning. They are older than him, but they understood him from when he could not speak. They will always pull him into play. He also has a little cousin, she is four years old, they love each other, and she has always understood everything he wants.”

The following caregiver describes the role her daughter has had, through play, in helping her child with ASD improve his non-verbal communication skills, including eye contact:

“The older child is proactive. She knows that her sister has the problem. She always gets down and plays with her. The other sister will come and say ‘Let’s play... focus’ [motions finger to eyes] ... ‘Look at my eye’. She is now looking people in the eyes.”

Family routines

Family routines spontaneously reported by caregivers, during which time they regularly interacted with their children, included two common daily living routines: mealtime and bath time.

Mealtime routines

Child participation during mealtime included the child saying prayers, helping to set the table, and washing dishes. The following caregiver describes their child leading the family in prayer before dinner:

“We always pray with him in the evening. He will call you and we will pray ‘Our Father’. One evening he stood in front of us before we ate, folded his arms (praying gesture), and then prays by himself. We cannot hear the words, but we know the sounds.

He did our father by himself from start to finish.”

In the next quote, a caregiver describes how her child helps prepare the table for mealtime:

“He normally sees somebody standing by the stove. He knows as soon as they take off the pots, we put on the plates. He knows that we are going to eat. Then he goes to his seat and waits. He opens the drawer and takes out the spoons and gives everyone a spoon. He knows as soon as we lay the plates, it is time to eat.”

Here, a caregiver describes her son helping with cleaning the dishes and asking to help with other household tasks. This activity also involves his grandmother:

“Grandma takes him to the washing line. Then he helps, he likes doing stuff for you, like washing dishes and asking, ‘mama can I help?’ And they have that time of bonding with the water, the cutlery and whatever.”

Bath time routines

Caregivers described using these daily interactions to teach their child names for body parts. In addition, they described engaging their child in social games and sharing positive affect.

This caregiver labels parts of the body with her child while bathing him:

“During bath time, you can teach him the parts of the body. You say, ‘this is the head’, ‘I am washing your face’, and he gets it. Because you do not have too much time to sit and work with your child. But at least you can use bath time for teaching. Everyday there is something that he gets. I can say one day, ‘I’m washing my fingers’ and he will say ‘fingers’.”

The following caregiver describes fun and games during bath time:

“Sometimes we do silly things and he likes that. When it is time to wash his face, I throw the rag up and say ‘catch’ and he will [gasp] and it is funny. Then I throw it to him, and he throws it back to me. He finds these unexpected things hilarious.”

Discussion

As efforts to address early intervention needs of young children with ASD increase around the globe (18), descriptions of joint activity routines will inform community NDBI implementation. The current study provides descriptions on where and how South African caregivers can embed NDBI strategies during ongoing daily caregiver-child interactions. While using objects during play, caregivers engaged in a variety of turn-taking games, taught cognitive, language, and fine motor skills, and participated

in child-directed activities. During sensory social routines, caregivers described active, physical play and an awareness of the child's emotions. Caregivers noted that their children showed increased expressive language and willingness to engage with different play partners during social games. In family routines, caregivers detailed child participation in mealtime and bath time, and noted increased child social communication during these routines.

There is limited literature on caregiver-child interactions, particularly when the child has a developmental delay or disability, in sub-Saharan Africa (3). A subtheme that emerged under sensory social routines, variety of play participants, may be a particularly relevant contextual factor in Africa, because of both the cross-cultural variability in adult involvement in child rearing, and the effects of the HIV/AIDS epidemic (32,35). South African caregivers noted that many people participate in activities and games with their children. This is common throughout sub-Saharan Africa, in part due to kinship systems and the concept of 'Ubuntu', or the interdependence of people on one another (35). For South Africa in particular, many black and coloured residents live in 'townships', previously racially segregated neighborhoods developed during the Apartheid, which may offer a source of community that provides relational support for youth (48). On the other hand, a diverse set of caregivers may be necessary in societies with higher rates of communicable disease and early death. South Africa has more people living with HIV/AIDS than any other country in the world, and more than 21 percent of South African children are living with neither of their biological parents (49,50). An additional contextual factor relevant to South Africa, that was clear from the focus group discussions, is language diversity. There are 11 official languages of South Africa, not including those of immigrants and refugees (41). Because caregivers and their children have matching cultural and linguistic backgrounds, caregivers likely have the contextual knowledge to promote growth in social communication skills. South African caregivers have reported that culture and language, respectively, may be challenges or barriers to early ASD intervention (51). Caregiver coaching may therefore be an important way to bridge this gap.

Several limitations may have influenced study results. First, a convenience sample of participants was utilized. Therefore, study participants may not be representative. However, participants racial/ethnic backgrounds match those of the Cape Town Metropole (41). Second, the Western Cape is one of the better-resourced areas in

South Africa, and this may affect the generalizability of study results to other South African provinces and African regions (44). Third, individual interview questions did not specifically focus on family routines. Although caregivers did spontaneously report mealtime and bath time routines, specific focus on family routines should be included in future qualitative enquiry to clearly understand how such routines may differ in South African families. Finally, no independent assessment of child ASD diagnosis was conducted. However, participants were recruited from the Western Cape Education Department Provincial ASD waiting list, and children's names are only added to this list once they have received a diagnosis from a developmental specialist.

Conclusions

Overall, the results suggest that South African caregivers of young children with ASD may already use joint activity routines to engage with their young children and incorporate teaching opportunities in these interactions. This suggests a degree of 'fit' between South African caregiver-child interactions and an NDBI-informed caregiver coaching approach. However, more information is needed on family routines in which NDBI strategies can be incorporated. Many South Africans routinely navigate poverty and health inequities (7). The economic resources and social and community support available to carry out daily activities may affect which joint activity routines occur within families (37). In addition, information on which caregiver interacts with the young child with ASD during these routines would provide additional knowledge on how to integrate NDBI-informed caregiver coaching and help tailor these interventions for low-resource African settings.

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Footnote

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Focus Group Question Guide

1. Please can you describe your child for us:
 - a. What is most important to you about your child's growth?
 - b. What are your short-term goals for your child?
 - c. What are your long-term goals for your child?
2. Does your child use any services for their autism?
 - a. What types of services does your child use?
 - b. What do you like or not like about these services?
 - c. What types of services would you like your child to receive?
 - d. What would the "best" autism service look like?
 - e. How useful are services for children with autism when they are very young?
3. We are interested in finding out more about how you play with your child.
 - a. Do you play with your child?
 - b. Are there other adults besides you that play with your child?
 - c. Can you tell us about the games you or other adults play with your child?
 - d. How do you know your child is having fun when you play with them?
4. What would you think about being taught how to do therapy with your child?
 - a. Would you be interested in learning how to do this type of therapy with your child?
 - b. What do you think would be easy about learning how to do this therapy with your child?
 - c. What do you think would be hard about learning how to do this therapy with your child?
 - d. What would you think about someone coming into your home to teach you how to do this with your child?
5. How do you think the following things would be important when making an autism treatment for families in South Africa?
 - a. Culture
 - b. Language
 - c. Where you get the treatment
 - d. Cost of the treatment
 - e. Who teaches you (for e.g. speech therapist or occupational therapist or community health worker)
 - f. How you already parent your child
 - g. How much time it takes to learn
 - h. How much support you have from your partner or other family members
 - i. Proof that the treatment works
 - j. How the treatment fits with your family needs
6. How do you feel about the use of video clips or photographs from local families who have helped us in our research? Is it useful or not useful? Appropriate or not appropriate?
7. Is there anything we missed?