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IMPLEMENTING THE EARLY START DENVER MODEL IN SENEGAL: OUTCOMES AND INSIGHTS FROM A LOW-RESOURCE CONTEXT

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SUMMARY

Background: *Autism Spectrum Disorders (ASD) are characterized by significant challenges in social interaction and communication, accompanied by repetitive behaviors. Effective early interventions, such as the Early Start Denver Model (ESDM) are crucial but primarily studied in well-resourced Western countries. This study explores the adaptation and effectiveness of ESDM in Senegal, a low-resource setting, to adress gaps in autism care and intervention accessibility in Africa.*

Subjects and Methods: *An observational study was conducted at Diamniadio Children's Hospital, Dakar, Senegal, from January 2019 to July 2021, focusing on children under 10 years suspected of having ASD. Diagnostic assessments were performed using the DSM-5 criteria with tools like the Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). Interventions based on ESDM were adapted to local resources and involved regular family and patient engagement.*

Results: *Of the 114 children referred for ASD suspicion, 80 were diagnosed with ASD. Post-diagnosis, 30 children received follow-up care at the day hospital, and another 30 were managed via outpatient care. 20 children did not receive any follow-up care at Diamniadio Children's Hospital. Significant socio-economic disparities were noted, influencing access to and engagement with intervention programs. No significant differences were found in clinical characteristics between groups, but socio-economic factors significantly affected intervention access.*

Conclusion: *The adapted ESDM interventions show promise for implementation in resource-limited settings like Senegal, although challenges related to socio-economic disparities and service accessibility persist. Future research should focus on the integration of ASD services into broader health policies to enhance efficacy and accessibility.*

Key words: *Autism Spectrum Disorder - Early Start Denver Model - Low-resource settings – Senegal - socio-economic disparities*

Abbreviations: *ADI-R - Autism Diagnostic Interview-Revised; ADOS-2 - Autism Diagnostic Observation Schedule, Second Edition; APA - American Psychiatric Association; ASD - Autism Spectrum Disorders; DSM-5 - Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; ESDM - Early Start Denver Model*

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INTRODUCTION

Autism Spectrum Disorders (ASD) are complex neurodevelopmental disorders that emerge in early childhood, characterized by impairments in social interaction, communication challenges, and the presence of repetitive behaviors and restricted interests, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (APA 2013). These disorders present a substantial burden due to the high prevalence and the frequent co-occurrence of intellectual disabilities and functional impairments. Consequently, developing and implementing effective interventions that can reduce symptoms and improve overall outcomes has become a pivotal goal in both clinical and research settings (Smith & Iadarola 2015).

The importance of early intervention in improving the prognosis of children with ASD is well-established, supported by a significant body of research indicating that early, structured interventions can lead to substantial improvements in functioning and development (Jones et al. 2017). Methods such as the Early Start Denver Model (ESDM), built for toddlers with ASD younger than 3 years, integrate principles from developmental and relationship theories with applied behavioral analysis techniques, creating a robust framework for enhancing communication and social skills through engaging, developmentally appropriate activities (Rogers & Dawson 2010).

Despite the known benefits of such interventions, the majority of evidence supporting these approaches originates from well-resourced, often Western settings. This leaves a significant gap in our understanding of how these interventions can be adapted and implemented in less-resourced, community-based settings, particularly in regions like Africa where public health and educational services often face significant constraints (Bailey et al. 2019).

In Africa, and particularly in Senegal, the landscape of autism care presents unique challenges. The continent as a whole has diverse healthcare systems and varying levels of resources. In many African countries, awareness

and understanding of ASD are limited, and the disorder is often stigmatized. This situation is compounded by a shortage of trained professionals and facilities dedicated to autism, making the diagnosis and management of ASD particularly difficult (Diallo et al. 2018).

In Senegal, the infrastructure for managing ASD is nascent and predominantly integrated within broader mental health services. Institutions like the Center for Education and Training of Children with Intellectual Disabilities (*Centre d'éducation et de formation des enfants déficients intellectuels*) and psychiatric units at hospitals, such as University Hospital of Fann and Thiaroye Psychiatric Hospital, provide services under a general framework that is not specifically tailored to the needs of children with ASD. These broader mental health infrastructures, while crucial, often lack the specialization required to implement structured programs like ESDM. Furthermore, day hospital services in these settings tend to focus on a broader spectrum of developmental and psychological disorders, without the focused intervention strategies that early ASD diagnosis and treatment demand.

This study aims to explore the feasibility and effectiveness of implementing structured, early interventions like the ESDM, within the Senegalese public health system. By adapting these methods to local conditions, we seek to address critical gaps in the current research and practice landscape and to examine the transferability of internationally recognized models to environments with vastly different resource availabilities.

SUBJECTS AND METHODS

Study Design and Participants

This study adopts an observational design, focusing on patients under 10 years old who are suspected of having ASD. The research was conducted at the pediatric psychiatry service of Diamniadio Children's Hospital, Dakar, Senegal, from January 2019 to July 2021, excluding school holidays. Patients can be referred by pediatricians, psychiatrists, schools, and child care centers, and parents can also request a consultation. Diagnostic assessments were carried out to determine if the patients met the DSM-5 criteria for ASD. These assessments included psychiatric clinical interview and the Autism Diagnostic Interview-Revised (ADI-R) and/or the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), administered by experienced clinicians. (Le Couteur & Lord 1994, Lord & Rutter 2012). If the ASD diagnosis was confirmed, the patient could either continue with outpatient care or be admitted to the day hospital.

Interventions

At the day hospital, interventions were based on the Early Start Denver Model (ESDM), adapted to the service's context and resource constraints. In accordance with the ESDM curriculum and teaching principles, for each child, an individualized intervention was developed to include a variety of objectives from all areas of development (communication, motor development, cognition, social interaction), as well as daily living skills. Interventions included three 4-hour sessions weekly (12 hours) of educational and play-based activities, conducted either in small groups or individually, aimed for a minimum of seven months. Trained educators, clinical psychologists, or child and adolescent psychiatrists conducted these sessions. Families, mainly parents, were also trained to apply these methods at home in order to reinforce the intervention's effects (Rogers & Dawson 2010).

Data Collection

Data collection combined sociodemographic information with clinical data. Sociodemographic data were gathered using structured questionnaires that detailed each child's age, sex, country of birth, family composition, parental professional status, and socioeconomic class. Clinical data were obtained from the patient's medical records. Information regarding follow-up at the day hospital was also collected.

Ethical Considerations

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The Ethics Committee of Cheikh Anta University approved the study. Written informed consent was obtained from all individual participants' guardians.

Statistical Analysis

Data were analyzed using IBM SPSS Statistics Version 26, employing descriptive statistics to summarize the data and inferential statistics to assess the effectiveness of the interventions. Differences between the two groups (follow-up at outpatient care and follow-up at day hospital) were evaluated using chi-square tests for categorical variables and t-tests for continuous variables.

RESULTS

Care Pathways

Figure 1 illustrates the care pathways at Diamniadio Children's Hospital in Dakar, Senegal, for children suspected of ASD between January 2019 and July 2021.

Out of 114 children referred during this period, 80 met the diagnostic criteria for ASD. Following diagnosis, the subsequent care pathways varied: 30 children were enrolled in follow-up care at the day hospital and

30 children were follow-up at outpatient care unit. 20 children did receive any type of follow-up care at Diamniadio Children's Hospital and were not included in the present study, mainly due to the COVID pandemics, parents refusing to accept the diagnosis of autism, and constraints related to geographical distance.

Sociodemographic Characteristics

Table 1 describes sociodemographic characteristics of the two groups (follow-up at day hospital and follow-up at outpatient unit).The average age of the children at the time of the study was 58.68 months (SD=22.58), with no significant difference between the two groups (p=0.808). Both groups had a similar gender distribution, family composition, birth order and parental professional status. A significant socio-economic disparity was noted between the groups; 76.7% of children that were followed-up at day hospital were from high socio-economic backgrounds, compared to only 33.3% in the second group (p=0.002).

Table 1. Sociodemographic characteristics of the sample and comparisons of the groups (n=60)

Variables	Day Hospital Follow-up (n=30)		Outpatient Unit Follow-up (n=30)		Total (n=60)		*p*-value
	Mean	SD	Mean	SD	Mean	SD	
Age (months)	57.97	20.62	59.40	24.72	58.68	22.58	0.808
	n	%	n	%	n	%	*p*-value
Sex							
Male	25	83.3	25	83.3	50	83.3	1.000
Female	5	16.7	5	16.7	10	16.7	
Country of birth [a]							
Senegal	23	76.7	20	69.0	43	72.9	0.567
Other	7	23.3	9	31.0	16	27.1	
Family composition [b]							
Nuclear family	23	79.3	25	83.3	48	81.4	0.748
Other	6	20.7	5	16.7	11	18.6	
Birth order [c]							
First-born	16	57.1	20	66.7	36	62.1	0.589
Later-born	12	42.9	10	33.3	22	37.9	
Parental professional status							
Both parents work	21	70.0	18	60.0	39	65.0	0.589
Other	9	30.0	12	40.0	21	35.0	
Socio-economic class							
High	23	76.7	10	33.3	33	55.0	*0.002*
Low-middle	7	23.3	20	66.7	27	45.0	

[a] Data is missing for one participant from the "Outpatient Unit Follow-up" group; [b] Data is missing for one participant from the "Day Hospital Follow-up" group; [c] Data is missing for two participants from the "Day Hospital Follow-up" group; SD - standard deviation

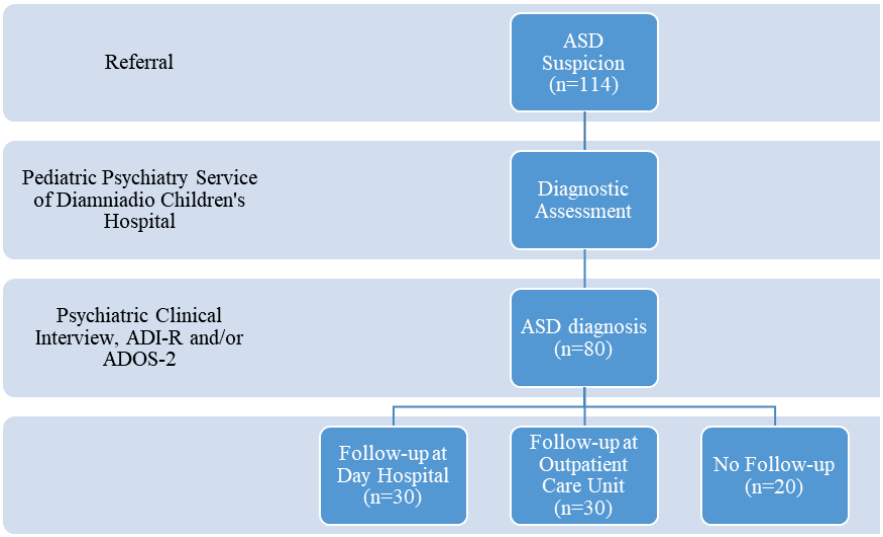

Figure 1. Care pathways at Diamniadio Children's Hospital, Dakar, Senegal, between January 2019 and July 2021, for children under suspicion of ASD

Table 2. Clinical characteristics of the sample and comparisons of the groups (n=60)

Variables	Day Hospital Follow-up (n=30)		Outpatient Unit Follow-up (n=30)		Total (n=60)		*p*-value
	n	%	n	%	n	%	
Medical disorder							
Yes	3	10.0	8	26.7	11	18.3	0.181
No	27	90.0	22	73.3	49	81.7	
Motor delay							
Yes	7	23.3	7	23.3	14	23.3	1.000
No	23	76.7	23	76.7	46	76.7	
Food selectivity							
Yes	20	66.7	20	66.7	40	66.7	1.000
No	10	33.3	10	33.3	20	33.3	
Sleep disorder							
Yes	9	30.0	9	30.0	18	30.0	1.000
No	21	70.0	21	70.0	42	70.0	
School attendance							
Yes	22	73.3	18	60.0	40	66.7	0.412
No	8	26.7	12	40.0	20	33.3	

Clinical Characteristics

Table 2 highlights the clinical characteristics of the two groups. While 10.0% of the follow-up group and 26.7% of the no follow-up group reported having a medical disorder, this difference was not statistically significant (p=0.181). Rates of motor delay, food selectivity, and sleep disorders were similar between the groups, with no statistically significant differences. School attendance was higher in the follow-up group (73.3%) compared to the no follow-up group (60.0%), although this difference did not reach statistical significance (p=0.412).

Follow-up Sample Characteristics

Table 3 presents characteristics specific to the follow-up at day hospital group, including the duration of follow-up, psychological assessment for comorbidities (intellectual disability, depression…), speech therapy, ADI-R scores, and parental training. 11 children (36.7%) were followed for 6 months or less, whereas 19 children (63.3%) had a longer follow-up period of more than 6 months. Most children (90.0%) underwent a psychological assessment, and a significant majority received speech therapy (86.7%). The diagnostic tests revealed that 86.2% of these children met the criteria for ASD based on the ADI-R score. Parental involvement through training was substantial, with 21 parents (70.0%) participating in training programs designed to support their children's development. However, 9 parents (30.0%) did not receive such training.

Table 3. Follow-up sample characteristics (n=30)

Variables	n	%
Follow-up time		
6 month or less	11	36.7
More than 6 month	19	63.3
Psychological assessment/comorbidity		
Yes	27	90.0
No	3	10.0
Speech therapy follow-up		
Yes	26	86.7
No	4	13.3
ADI-R score [a]		
ASD	25	86.2
No ASD	4	13.8
ADOS-2 [b]		
Testable	12	50.0
Non testable	12	50.0
Parental training		
Yes	21	70.0
No	9	30.0

[a] Data is missing for one participant;
[b] Data is missing for six participants

DISCUSSION

The present study explored the feasibility and effectiveness of the Early Start Denver Model (ESDM) in a resource-limited setting such as Senegal, focusing on sociodemographic and clinical characteristics of children diagnosed with Autism Spectrum Disorder (ASD). This comparison aimed to determine which socio-economic and clinical profiles have access to these types of interventions, thereby providing insights into the distribution and accessibility of structured support strategies within these constraints (Franz et al. 2017, Viljoen et al. 2021).

The study demonstrated no significant difference in clinical characteristics, such as medical disorders, motor delays, food selectivity, or sleep disturbances between the two groups. However, patients who were followed up at the day hospital showed higher rates of school

attendance. This may suggest certain benefits of the intervention in enhancing educational engagement, although these results did not reach statistical significance (Dawson-Squibb et al. 2020).

Our findings suggest that structured interventions like ESDM can be adapted and potentially effective in resource-limited settings. However, significant socio-economic disparities between the groups underscore the challenges and disparities in access to specialized interventions. Reasons for no follow-up (both at day hospital or outpatient unit) included logistical challenges such as distance from the hospital and cultural resistance to diagnosis (Divan et al. 2021). Other barriers can limit participation in the day hospital care program, reflecting broader issues in the Senegalese healthcare system, such as, the diagnostic age and parental availability. These findings suggest the need for broader community education about ASD and more accessible intervention programs.

These findings align with previous studies which identified significant gaps in ASD service provision in Sub-Saharan Africa. These authors discussed the importance of considering parents' perspectives on the functioning of their children with ASD, which can influence the effectiveness of developed interventions. To improve outcomes across all socio-economic levels, policy interventions are needed to ensure equitable access to resources and supports. Implementing policies such as government-subsidized health services specifically for ASD could enhance the accessibility and impact of interventions like ESDM (Franz et al. 2017, Viljoen et al. 2021). Also, not all families could participate in the intervention training sessions due to conflicting work schedules or other responsibilities, indicating a need for more flexible, accessible training solutions for parents and caregivers involved in ASD care.

Limitations and Future Research

The study encountered several limitations, including the small sample size and the lack of a randomized controlled trial design, which could affect the generalizability of the results. Additionally, data collection was limited to a unique cultural and geographical context, which may not reflect broader regional differences within Senegal or in other African countries. Future research should aim to include larger and more diverse populations and consider longitudinal designs to assess the long-term impacts of these interventions. Moreover, the adaptation of ESDM to the local context, while necessary, could have influenced the fidelity and effectiveness of the intervention. Future studies should explore the specific adaptations made and their impacts on outcomes to better understand how to implement these interventions effectively in similar contexts.

CONCLUSION

This study explored the implementation of the ESDM in a resource-limited setting within the Senegalese public health system. The findings underscore the potential of structured, evidence-based interventions to enhance the developmental trajectories of children with ASD, even in environments challenged by limited resources and significant socio-economic disparities.

The adaptation of ESDM to the local context, while presenting several challenges, has shown promising results in improving the clinical and developmental outcomes of the children involved. Notably, the study highlighted that accessibility to such interventions is profoundly influenced by socio-economic factors, which can limit the reach and effectiveness of these programs. Significant disparities in intervention access suggest a critical need for policy reforms aimed at increasing the availability and affordability of specialized autism care across different socio-economic groups.

Future research should focus on longitudinal studies to track long-term outcomes, explore more diverse populations, and investigate the efficacy of various intervention models tailored to specific community needs.

In conclusion, while the challenges are significant, the benefits of implementing structured interventions like ESDM in underserved regions are compelling. These interventions not only promote better outcomes for children with ASD but also set a foundation for more inclusive health and educational services that can adapt to the diverse needs of the population.

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Contribution of individual authors:

Ndeye Awa Der Dieye: design of the study, literature searches, collection and interpretation of data, manuscript writing and editing.

Joana Reis: literature searches and analyses, statistical analysis, interpretation of data, manuscript writing and editing.

Véronique Delvenne: design of the study, literature searches, interpretation of data, manuscript writing and editing, revision.

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