Information-seeking Behaviour of Parents of Students with NDD: A Case Study of Parents of Students with Intellectual Disability

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Abstract--- Information is extremely vital for human existence, however, searching for the right information at a particular point in time is quite challenging. In the context of this research, information-seeking behaviour of parentsentails the kind of behaviour that parents exhibit in orderto have access to the required information for their child with intellectual disability (ID). There is a paucity of literature with respect to information-seeking behaviour of parents of children with ID. The present study intends to close this lacuna by exploring the information-seeking behaviour of parentsof students with ID in the Nigerian context. Through a qualitative research approach, six (6) participants who were selected using a purposive sampling technique were studied. The instrument for data collection was a semi-structured interview. Three themes emerged from the data analysis. The study showed that information-seeking behaviour of parents of students with ID is characterised by consulting close family members, friends, professionals, reading books and surfing internet. Therefore, the study established the framework of information-seeking behaviour of parents of students with ID in the Nigerian context.

Keywords--- Information-seeking Behaviour, Intellectual Disability, Learning Needs, Nigeria, Parents, Students.

I. Introduction

Neuro developmental disorders (NDD) are a group of conditions involving the nervous system and characterized by difficulty in personal, social, academic, and occupational functioning that occurs during the development process (American Psychiatric Association [APA], 2013). Students diagnosed with NDD commonly experience difficulty associated with motor skills, behaviour, memory, language and speech, and learning which is subject to change throughout individual student's life. Some categories of NDD include attention deficit hyperactivity disorder, autism spectrum disorder, specific learning disability and intellectual disability. Intellectual disability (ID) refers to a varied sort of disabilities manifested by long-term limitations in cognitive functioning ability and comprised of adaptive and intellectual deficits within conceptual, social, and practical areas (APA, 2013). Students with ID are characterized by delays in intellectual functioning such as reasoning, abstract thinking, judgement, problem solving, planning and learning from experience. Students with ID exhibit delay in areas of adaptive functioning which may appear immature in their social interaction and could manifest in struggle to regulate emotions, misread social cues, and may behave in age-inappropriate ways (Faulconbridge, 2021).Students diagnosed with ID are further classified by severity of need, including mild, moderate, severe, and profound categories and the global prevalence of these ID categories ranges from 0.05 to 1.55% (APA, 2013; McKenzie et al., 2016). Students associated with ID have difficulty in problem-solving, planning, communication, and daily activities across families, schools, work and community life (Liesemer, 2022).

The educational cost of students with ID is huge because due to their low academic performance, they spend more than the required number of years in school. Adeleke et al (2020) indicated that there is a substantial relationship between ID prevalence and family poverty. Many individuals with ID find it difficult to secure employment after school, making parents more concerned about the economic survival of their child diagnosed with ID (Adeleke et al., 2020). Parents who support their child with ID often experience financial and social challenges due to the high cost and social limitations of raising a child with ID. Thus, parents of a child with ID often value vital information that would lead to the enhancement of their child's academic performance.These parents may frequently seek for health information and tend to connect to a strong peer network that provides reliable information which is an essential aspect of raising a happy, healthy child, safeguarding family well-being and building emotional resilience.

Information-seeking behaviour entails parents searching, browsing, organizing, storing, using and sharing sometimes highly specialized information related to their children's particular diagnoses and needs (Rodrigue, et al. 1992). Information-seeking behaviour is often assumed to be rational and oriented towards making an important decision and relatively simple judgements about the value of such decisions (Case & Given, 2016). It is of utmost importance that the parents of students with ID are adequately informed and provided with information counselling to reduce the anxiety of the parents and their children (Medha, 2020). In this regard, counsellors in school, teachers and psychologists play a significant role in educating parents as well as changing their perspective about their children with ID. Currently, there is limited information available on the information-seeking behaviour of parents of students with ID. Hence, there is need to establish the information-seeking behaviour of parents of students with ID since it would go a long way in assisting the students in coping with academic activities.

Several related studies have been conducted with respect to information-seeking behaviour of parents of students with neurodevelopmental learning needs. Mackintosh et al. (2005) examined the sources of information and support for parents of children with ASD. The findings revealed that written materials were the main source of information compared to information obtained through face-to-face contact. In addition, Twombly et al. (2011) in study of information behaviour of ASD caregivers revealed that only internet usage for caregiving information characterised their behaviour. Grant et al. (2016) found that the majority of parents in their study desired a change in the style of information and content as well as reported information sources such as ASD workshops or decision-making services. Also, Gibson et al. (2017) in a survey study revealed that the majority of information sought by parents came from local sources rather than nonlocal sources. In previous studies, survey research was used to elicit information from participants. However, the current study employed a qualitative approach to amass lived experiences of participants.

Study conducted by Medha (2020) on the information requirement of parents of children with learning disabilities using survey research approach found that parents preferred information from family, friends and school counsellors. In addition, Medha revealed that these parents sought information on the best way to manage their children's behaviour and their academic performance, as well as what other parents were experiencing. Furthermore, Lwogaand Mosha (2013) investigated the information-seeking behaviour of parents and caregivers of children with mental illness using an online survey and found that access to and use of the internet was the main means of health information-seeking while others areverbal discussions with family and television. These studies conducted by Medha (2020) and Lwoga and Mosha (2013) utilised a survey research design in which questionnaires were used for data collection process, hence, real life experiences of the participants were not explored. Therefore, this study employed a qualitative approach to elicit information from parents of students with ID with respect to their information-seeking behaviour.

Sahay et al. (2013) investigated the parents of children with ID and the report showed that parents are enthusiastic about seeking information about present and forthcoming services prevailing in society and the community, expenses associated with caring for the child, education and treatment. Jackson et al. (2008) in a study of parents' information needs revealed that parents desire verbal information from professionals, along with overall information concerning the disability and specific information regarding their child's condition. The research by Sahay et al. (2013) that employed mixed-method design and Jackson et al. (2008) that used qualitative approach did not specifically focus on students with ID or the information-seeking behaviour of their parents. Hence, this study unveiled the information-seeking behaviour of parents of students with ID in the Nigerian context.

Nigerian Context
The way Nigerians perceive students with ID is affected by culture and religion. Students that have symptoms of ID in Nigeria are neglected by peers and sometimes by family members. Cases abound where individuals with ID are murdered for rituals or as a practice in line with indigenous religious belief (Etieyibo & Omiegbe, 2016). This attitude of Nigerians towards students with ID has led to human rights abuses, discrimination, a negative stance towards the child and family, and lack of social acceptance (Arimoro 2019). Arimoro disclosed that some women with ID have become sexual assault victims, many of whom are displaced and wander the streets while their parents sometimes show mixed emotions towards them. This implies that whilesome parents show positive attitudes towards their children with ID, some othersdo show a feeling of misery and fury towards them. This could be attributed to its effects such as dedicated time, functional costs, physical and emotional demands and logistic complications related to providing care for the affected child (Adeleke et al., 2020). These scholars emphasized that students with ID are sources of financial burden to the parents because their educational and medical costs are enormous as a result of absence of free health care and inadequate social services for these students in Nigeria. Some of these students may overstay in their schools as a result of academic challenges and may end up being withdrawn from their respective schools. This may impact negatively on society as these students with ID may not be engaged in active labour force in order to contribute to society thereby increasing the rate of dependence in society. The parents may also be at a

high rate of experiencing poverty since there is no government assistance in this regard in Nigerian society (Adeleke et al., 2020).

Literature has shown that studies conducted in Nigeria concerning the information-seeking behaviour of parents of students with ID are scanty. Some other related studies have been conducted on information-seeking behaviour with a different focus. A survey research conducted by Adeleke et al. (2020) on the impact of ID on the family economy found that ID has substantial negative effects on the family economy and education of siblings and person with ID. This study conducted by Adeleke et al. is a correlational survey that established relationship between the study variables using a questionnaire while this current study utilized qualitative approach involving interview to investigate the information-seeking behaviour of parents concerning their children with ID.

Similarly, Orim, and Ezekiel (2017) used survey study to investigate the incidence of distinctive learning disabilities and its management among pupils and it was revealed that eight subtypes of learning disabilities were identified which include dyslexia (26%), dyscalculia (18%), dysgraphia (16%), ADHD (9%), dyspraxia (15%), dysorthgraphia (3%), dyspinxia (8%) and dysmusia (5%). The study found that specific learning disabilities are poorly managed by teachers. While Orim and Ezekiel's work established different kinds of learning disabilities that exist in Nigeria, this current study explored first-hand information from the parents of students with ID based on their information-seeking behaviour to enhance the academic conditions of their children.

Okoli and Azubuike (2021) conducted a survey study on the information needs and information-seeking behaviour of Nigerian secondary school teachers and it was disclosed that teachers need information and therefore search information to fulfil their several needs. This study did not disclose the kind of information-seeking behaviour these teachers seek and the study did not focus on students with ID. Furthermore, Adeyinka et al. (2017) assessed the information-seeking behaviour of physically challenged students using a survey research design and found that the participants seek educational information through lecture notes/handouts, as well as consult the services of librarians on reference services, abstracting, and indexing services. Wiche and Ray-Ogbonna (2021) investigated information need and seeking behaviour among medical students using a quantitative survey approach and it was disclosed that students checkseveralmeans when seeking information such as medical textbooks, classmates, library, school notice board, internet, ebooks among others. These empirical studies on information-seeking behaviours were conducted in different areas, such as teachers (Okoli & Azubuike 2021), physically challenged students (Adeyinka et al., 2017), medical students (Wiche & Ray-Ogbonna 2021). Therefore, there is a lacuna in literature based on the information-seeking behaviour of parents of students with ID which this current study investigated. Generally, these reviewed studies were conducted using a survey research approach in which questionnaires were the main instrument for data collection. This current study adopted a qualitative approach using face-to-face interview to elicit information on the lived experiences of the participants.

II. Theoretical Framework

This study anchored on the Wilson Model of Information Behaviour (Wilson, 1981) to explain information-seeking behaviour of parents of students with neurodevelopmental learning needs. The model emphasizes that information-seeking behaviour is a result of the perceived needs of people who use information at different stages of their lives. Therefore, to fulfil these needs, people request information through formal and informal sources which could result in success or failure to find important information. This model is related to this study because parents of students with ID seek information in different ways based on their environment, their level of knowledge, and their ability to afford the information. Wilson emphasized that information-seeking behaviour may comprise of different individuals engaging in information exchange in which information that seems to be useful is shared with other individuals who need it. This implies that the parents of students with ID make decisions either to take the information or not by subjecting it to value judgement (Case & Given, 2016). Wilson and Walsh (1996) noted that information-seeking behaviour involves inactive attention and search, active search and on-going search. This indicates that the level of engagement by parents of students with ID in seeking for valuable information to enhance academic performance and social well-being of their child could be categorised as active or passive search.

This study equally anchored on Cheuk Wai-Yi (1998) Information-Seeking and Using (ISU) Process Model. This model demonstrates thatdepending on the circumstances, each individual displays a dynamic and diverse information-seeking behaviour. This model outlined some crucial and information-seeking aspects which include task initiating, focus forming, ideas assuming, ideas confirming, ideas rejecting, ideas finalising, and the passing on of ideas. This model emphasized that information seekers pass through these stages of information to acquire reliable and valuable information for personal or organisational needs. These identified stages are what literature has shown that majority of individuals' information-seeking behaviour passes through in order to obtain valuable information that could enhance the performance of their children. Parents of students with ID explore these stages in search of vital information that could help elevate the academic burden on their children diagnosed with ID.

III. Method

The design of this study is a phenomenological research design. According to Donalek (2004), phenomenological research investigates individuals' lived experiences through the explanation rendered by the individuals that are concerned. The objective of phenomenological research is to examine the lived experiences of the subject and this kind of study is conducted in an area where there is little knowledge. This design is suitable for this kind of study because it investigated the information-seeking behaviour of parents of students with ID. Parents' lived experiences concerning seeking information for their child's well-being is a novel area of research in south-east Nigeria.

Emails were sent to special schools in south-east Nigeria (n=3). The participants for the study were selected based on havinga child with ID. Thus, the study adopted a purposive sampling method to recruit 6 parents that their child has ID, of which 4 were females and 2 were males. The age range of these participants was from 35 to 60. The lead interviewer ensured that participants signed a consent form and entered demographic information prior to the interview. Ethical clearance for this research was approved by Faculty of Education Research Ethics Committee at the University of Nigeria.

Structured interview questions on information-seeking behaviour of parents were adapted from Gibson et al. (2017) to elicit information on the lived experiences of parents of children with ID. Two preliminary questions were posed to the participants to elicit information on their biodata. Furthermore, 11 interview questions were administered to the participants to elicit information on their lived experiences. The team that conducted this interview were three Ph.D holders. This team made sure that participants were in good spirits to respond to questions before scheduling the interview. Therefore, suitable times that were convenient for participants were strictly followed. The interviewers had the opportunity of exploring the amassed lived experiences of participants concerning their information-seeking behaviour. The recruited participants were informed that their responses would be recorded during the interview. In addition, the participants were notified that direct quotations from their responses could be utilised in publication related to the project. However, identification of their name or school will not be possible. Data collected were stored on a protected laptop while paper recording was secured and could beaccessedby the research team alone. Participants were guaranteed that the recorded data would be deleted as soon as anonymization and transcription were completed.

This study adopted reflexive thematic analysis which enabled a rich detailed analysis of qualitative data following an iterative and cyclical approach (Braun & Clarke 2006; Clarke & Braun 2016). Transcripts were checked alongside audio recordings. In order to become familiar with the data collected, multiple readings were done considering the main topic and interest of the participants, related ideas and early thought on possible areas of importance. Through this process, initial codes were generated. These codes enabled the identification of patterns and related codes. The objective of the study was utilised as a guide in selecting which codes were important for data analysis and themes were utilised to group together codes that were related to create a central idea. Codes and themes were studiedin conjunction with the coded extractsindicating an iterative process. Based on this process, themes were identified.

IV. Results and Discussion

The findings of this study were presented in three themes which include consulting family and friends, consulting professionals, reading books and searching online for solutions (Figure 1).
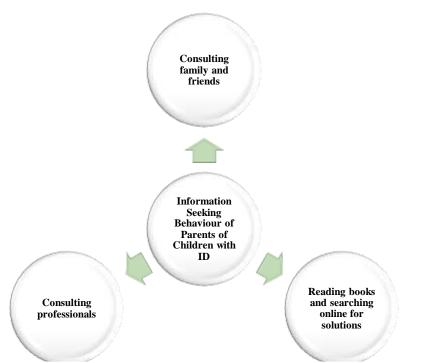
Figure 1: Framework of information-seeking behaviour of parents of students with ID

Consulting Family and Friends

The selected participants shared their lived experiences concerning seeking information from close family and friends on vital information that would enhance their children's academic performance. For instance, "…after several days of reflecting on my daughter's academic performance, I decided to seek advice from my senior…. And she suggested that I should try to gether a private teacher, so that the teacher could help in re-teaching her what was taught in school as well as assisting her with homework. I adopted her suggestion and that has been helpful even though it cost more money" [01].

Seeking information from a family member was identified as the first option by the majority of participants. Some of the participants revealed that their relatives support them with learning material and some finance; hence, they seek their opinions when their children are lagging behind in their academic journey. "I always call my brother at the end of every term to inform him of my children's performance in school and seek his advice for some that did not do well to my expectations. There was a time when he advised me to relocate my child with ID to another school but after considering the distance and money involved, his advice was not taken" [04]. This was supported by participant [02] who said: "My relatives always advise me to withdraw my child from her present school due to her performance, but I declined due to additional stress of taking her to a new school. However, I took the advice of my senior sister to enrol her in evening class which she now attends three times a week". Consulting family members was perceived by the majority of the participants as valuable and reliable means of seeking information for their children with ID. However, other respondents admitted that they equally consult their friends especially those that have knowledge of ID. Participant [03] recounted how he contacted his old classmate that teaches in secondary school about his son's poor performance, "I prefer consulting my friend regarding the poor performance of my son because he is an experienced educator who has almost 12 years of teaching experience. All the experience he shared with me was exceptional. Sometimes, I call another friend of mine whose child also had a similar issue in the past and he always supplies me with ideas".

Several participants have found it helpful to consult friends if their family members are not knowledgeable about how to assist students with ID. One of the participants revealed that she preferred consulting reliable friends because they always shared their lived experiences which were not known to her before but are effective."I always share with my friends the low performance of my daughter and her attitude towards school in general and the feedback I got from them has been impactful" [06].

Consulting Professionals

Professionals in this context are educational psychologists, therapists, and guidance and counselling experts. Some of the participants expressed their experiences with these specialists concerning the advice they received from

them. For instance, a participant [05] said that she prefers seeking the advice of an educational psychologist on the issue of her son's learning disability.

"I began consulting with a friend who studied educational psychology when my son took the last position in his class. I was really devastated that I didn't know what to do. I summoned [the] courage to consult her and she made me understand that it is a natural phenomenon that has a solution. She changed my conceptions about my son's academic challenges because I was thinking that something else (witches or wizards) was responsible. …Since I started following her recommendations, I noticed a progress…."

Seeking the advice of professionals in terms of assisting children with ID was prioritised by the participants. However, these participants seek solace in different professionals as some look up to educational psychologists while others seek advice from school counsellors. …I prefer talking to school counsellors because they possess enough knowledge of factors that affect students' learning disability. …the counsellor I met recently requested that I should come with my son…. after interacting with him, he promised to monitor his activities at school [04]. Another participant [02] made a useful revelation concerning school counsellors' activities in school. "…School counsellors are grounded in learning activities and what constitute learning disabilities. I prioritise consulting them with respect to my child's academic challenges. Their advice is top-notch". Contrary to the revelation of participant 02, another participant [03] said that he sought information frequently from psychotherapists than counsellors because some counsellors are prone to protecting the interests of their school while giving recommendations. Psychotherapists are my first line of action, anytime I need professional advice because they are impartial regarding children's learning disability.....some counsellors would not be apt on this issue of impact of school and teachers' variables on students' learning disability. "

Reading Books and Searching Online for Solutions

Reading books and surfing the internet were the least options the participants pointed out in seeking information on how to assist their children with ID cope with learning difficult. Participant [05] said that she read more on the solution textbook both online and offline to acquire more knowledge with respect to advice she received from family or friends as well as professionals. …. "reading book enables me to take proper decisions on information I got from consultations. Knowledge I acquire from books allows me to confirm the recommendations and suggestions made by the experts". A participant [03] noted that he surfs the internet constantly to explore the emerging solutions for students with ID, as well as review comment sections to learn what readers think about some of these solutions. "I prefer reading online because there is a paucity of local author textbooks on students with ID – online textbooks and journals – since they are enriched with lived experiences and solutions for assisting students with ID". Participant [01] equally emphasized that online materials provide practical guidelines on how both parents and teachers can assist students ID cope with learning challenges.However, participant [06] revealed that she is not computer competent, hence, she does not surf the internet but reads books in other acquire more knowledge with respect to assisting her daughter learn in school. …"computer is not for an old woman like me, because I do not have enough skill to manipulate them. I prefer reading hardcopy materials to acquire more knowledge. Sometimes, my grown-up children download information from online and print it for me to read which has been helpful".

This study identified the information-seeking behaviour of parents with ID to include consulting family and friends, professionals and reading and searching information online. This study disclosed that majority of the participants sought information from their family members and friends concerning their children's academic challenges. Most of these participants felt they are secured while sourcing for information from their family and trusted friends and these discussions sometimes emanate when they ask about their children's academic performance. The present finding could be attributed to the natural human urge to source information from the immediate environment when they encounter challenges even though the source may not be expected in the area. The finding of this study aligned with Sahay et al. (2013) who revealed that parents are enthusiastic about seeking information on current and future services available in society and the community, expenses associated with caring for the child, education and treatment.

This study revealed that participants seek information from professionals. This could be attributed to the efficiency and effectiveness of these professionals in rendering special advice to individuals. Some of these professionals include educational psychologists and school counsellors. According to American Psychological Association (APA, 2022), psychologists are grounded on disability issues and mental health as well as the influence of environmental factors on students' academic activities. This is because they have acquired sufficient knowledge through training in different areas such as cognitive, affective and psychomotor domains that influence students' performance. The school counsellors are trained to guide and render academic advice to students including those with learning disabilities. They are well-equipped with knowledge to curtail the daily academic challenges of students with ID. The finding of this study also lends support to Jackson et al. (2008) who revealed that parents desire verbal information from professionals, along with general information about the disability and specific

information of their child's condition. In affirmation with the finding of this, Medha (2020) found that parents preferred information from school counsellors. School counsellors know the challenges students encounter in the school setting which could be due to environmental or human factors, and they possess the required knowledge to give advice to students to combat such challenges.

This present study revealed that participants seek information by reading and searching for information online. Several scholars have publishedarticles in journals which explored the effectiveness of intervention programmes on individual students with ID. There also well written test books that explored the symptoms, identification and management of individuals with ID and are available both offline and online for personal coaching. Some of the participants preferred sourcing the information through hand books or hardcopies while others preferred sourcing the information online. They revealed that knowledge they acquired through reading served as a source of support and confirmation of orally sourced information. This study is in agreement with Kamba (2010) who revealed that respondents utilised the internet and other electronic resources and also prefer reading printed materials for their activities. This finding equally lend a support to Lwogaand Mosha (2013) who found that access to and use of the internet was the main source of health information-seeking followed by verbal discussions with family and television.

The finding of this study has practical implications for parents of students with ID and students with ID in south-east Nigeria. The information-seeking behaviour of the participants was primarily focused on getting information from personal experiences or from the lived experiences of their relatives and friends. This means that most of them manage their children's ID with limited knowledge they acquired from non-experts without taking into cognisance the severity of their child's ID. This study has unveiled the nature of the information-seeking behaviour of parents of students with ID to social workers, therapists, and school counsellors. It appears to have exposed a lacuna in the services of school counsellors especially in counselling parents of children with ID.This study has provided educational stakeholder a clue to understand the information-seeking behaviour of parents of students with ID. The findings of this study would help the educational stakeholders as well as the ministry of education to make adequate provision that would assist students with ID and well as provide a channel of feedback to their respective parents. This study also revealed that while parents of students with ID consult professionals like psychologists and school counsellors, they devote also more time and energy to seeking support beyond the school environment in order to enhance the academic status of their children with ID.

V. Conclusion

This study explored information-seeking information of parents of students with neurodevelopmental learning needs specifically intellectual disability. Through qualitative, phenomenological research approach, this study disclosed that information-seeking of parents of students with ID is characterised by consulting close family members, friends, professionals, reading books and surfing internet. This study has made a significant contribution to knowledge in regards to information-seeking behaviour of parents of students with ID in south-east Nigeria.

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