The Prevalence, Identification Process and Intervention Strategies of Children with Intellectual Disabilities: A Report of an Institution's Fieldwork

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Abstract

The writers of this paper presented a report of an institution of a fieldwork conducted in 2014, which used own identification process and intervention strategies to attend to the children with intellectual disabilities. The report gave the history and foundation of the institution and its programmes, which range from vocational training, special education services, reading instructions that provided individual instruction for children, physiotherapy services, and lots more. The paper reported the prevalence of intellectual disabilities in the centre, as well as the identification process adopted by the institution, as against the general identification process for children with intellectual disabilities; the various adopted intervention strategies the centre used to meet the individual needs of the children were discussed. Other important aspects of the centre's programmes is the parental involvement in the educational programme of the children and the myriad of scholarships and grants the centre and the children received from the local and international organizations were highlighted by the report.

1. Introduction

Professionals in special education and parents hope to make their students and children with intellectual disabilities better and independent to themselves and the society, and be able to achieve in relation to the expectations of a society in which intelligence is highly valued. So, children with intellectual disabilities and their parents are at risk of being underestimated and stigmatized (Lindsey, 2003). Children with intellectual disabilities and their parents have to come to terms with this condition and will preferably adopt a different set of values, based on the inherent worth of every individual that focuses on strengths rather than weaknesses. Professionals and institutions working with people with intellectual disabilities should be aware of these issues and consider their own values, methods, philosophies and guidelines to ensure that they respond appropriately to the children with intellectual disabilities that they attend to and also to their families. This may actually be reflected in the ways the institutions or centres adopt own identification process and intervention strategies to meet the individual needs of the children with intellectual disabilities in their institutions.

Intellectual disability may be identified at any time in childhood or adolescence, but generally the more severe the disability, the earlier it will be noticed. Children with Down's syndrome are usually diagnosed soon after birth because of their physical characteristics, whereas those with a mild intellectual disability and no physical

differences may not be diagnosed until they start to experience difficulties in childhood and adolescence. The diagnosis of moderate or severe intellectual disability is usually made by a qualified medical doctor, however, their learning difficulties may be identified educationally when they are early identified and referred by the teachers. A diagnosis of intellectual disability is made with good practice and guidelines by the centres and institutions, where professionals thereafter communicate the diagnosis with parents at the time of diagnosis.

Intellectual Disabilities (ID) is a neurodevelopmental disorder with multiple etiologies that is characterized by deficits in intellectual and adaptive functioning presenting before 18 years of age. ID encompasses a broad spectrum of functioning, disability, and strengths. The term improves upon and replaces the older term, mental retardation. The term global developmental delay is used to describe children younger than age five who fail to meet expected developmental milestones and have deficits in multiple areas of functioning. Mental retardation (MR), or intellectual disability (ID), is a descriptive term for subaverage intelligence and impaired adaptive functioning arising in the developmental period (below 18 years). It is a condition of arrested or incomplete development of the mind. ID is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. ID however, is the most common developmental disorder. Its prevalence cuts across races, colours, social economic status. Its effect on the individual, family, and community can be immense, since most individuals are affected from an early age.

ID however, is known by different names in different countries. According to data collected from 147 countries, some common terminology is: mental retardation (most common term in 76% of the countries), intellectual disability (57%), mental handicap/ disability (~ 40%). Other terms like learning/developmental disability and mental deficiency/subnormality are also used (WHO, 2007). For the purpose of this paper, the 'Intellectual disabilities' means same as 'mental retardation'. The preference is based on the global contemporary use of term in special needs education. Intellectual disabilities, with lower intellectual functioning could lead to reduced ability to adapt to the needs of daily living (Maulik & Harbour, 2010).

The writers of this paper therefore, present a report of an institution of a fieldwork conducted in 2014, which uses own identification process and intervention strategies to attend to the children with intellectual disabilities. The report therefore, gives the history and foundation of the institution and its programmes; reports the identification process adopted by the institution, as against the general identification process for children with intellectual disabilities; the various adopted intervention strategies the centre uses to meet the individual needs of the children will be discussed. The crucial aspect of the centre's programmes is the parental involvement in the educational programme of the children, which the report will highlight.

2. Open Doors for Special Learners Jos, Nigeria

Open Doors for Special Learners, Jos is a registered non-governmental and not for profit organization dedicated to the provision of quality Special Education, vocational training, speech and language therapy and physiotherapy for children and youths with learning. The task of the centre also includes provision of opportunities for individuals with reading difficulties to develop literacy skills in the Reading Clinic, and the expansion and upgrading of quality education for children with special needs through teacher training and advocacy (Open doors Special Education Centre, 2015). The centre was established in October 1999 by a retired Professor of Special Education, who registered the centre with the Corporate Affairs Commission as a non for profit, charitable NGO under the management of a Board of Trustees and a Board of Governors. The main function of the NGO is to run the Open Doors Special Education Centre located in Jos, Plateau State, Nigeria. The Centre started functioning in 1999 in a temporary location in Jos and moved to its permanent site in 2003.

The centre operates in units that comprise of: vocational training, special education unit, reading clinic and physiotherapy services. The children with ID in the centre equally benefit from other instructional services. Each unit performs the following roles:

Vocational Training: Since children with an intellectual disability do not have the ability to pursue an academic course, it is very important for the centre to prepare them for independent and useful adult lives. Children are enrolled in the centre's vocational training programme with the main vocational activities of cooking, hair braiding, production of candles, pomade, and pavement blocks as well as farming during the raining season. The centre equally runs physiotherapy services for group of children with cerebral palsy and other orthopedic clients.

Special Education Unit: The children in this Unit are placed in Class/ Levels starting from Level One which are early intervention classes through Level Six and Pre-Vocational level. Each class/ level population is small so that the children can benefit from individualized attention. The curriculum in this unit focuses on language development and basic literacy and numeracy skills with an emphasis on self-help skills.

Reading Clinic: This Clinic provides individual instruction for children, youth and adults whose difficulties in reading and writing prevent them from achieving their academic and independent full potential. These students attend the reading clinic by appointment on an hourly basis.

Most of the children in the centre enjoy scholarships. There are lots of children on either full or partial sponsorships from various religion groups, Non- governmental organization, and rich individuals and international sponsors that are showing benevolence to the education of this group of children. Some private individuals sponsor specific children while others make occasional donations towards sponsorship. However, since sponsorship donations are irregular, the Centre cannot rely on the payment of the fees for these children (Opendoors Special Education Centre, 2015).

3. Prevalence of Intellectual Disabilities in the Centre

The term 'prevalence' of intellectual or developmental disabilities usually refers to the estimated population of people who are managing Intellectual or developmental disabilities at any given time. The rate of emotional and behavioural problems is much higher in children and adolescents with intellectual disability than in the general population. Most studies have found prevalence rates of 40-50%, although there is very poor access to and use of mental health services. Between 5% and 15% of children with intellectual disabilities have behavioural problems that present a significant challenge to those caring for them. In many cases these problems cannot be adequately described by current diagnostic classification systems (ICD-10 and DSM-IV). The prevalence of ID in the general population is approximately 1/100; prevalence for severe ID is approximately 6/1,000 (APA, 2013).

In Open Doors for Special Learners, children with intellectual disabilities (ID) are often confused with children with Down Syndrome, autism, cerebral palsy and other developmental disabilities. However, going by the definition of ID of "deficits in intellectual and adaptive functioning", the prevalence of ID in the centre are as follow:

Level 1: One (1) child, a girl is identified out of the total number of 16 children.

Level 2: Two (2) children, both boys are identified out of the total number of 11 children.

Level 3: This Level comprises of two arms with the total number of 22 children. Three (3) boys and one (1) girl with ID are identified.

Level 4: Three (3) children, all girls are identified out of 9 children.

Level 5: The population of children in this level is 10, in which four (4) boys and two (2) girls are identified as children with ID

Level 6/Pre-vocational: Five (5) boys and three (3) girls out of the total number of 17 children are identified.

The centre with the population of 85 children, with varying types of handicapping conditions, has the total number of twenty-four (24) children (14 boys, 10girls) identified with Intellectual Disabilities.

4. Identification of Intellectual Disabilities in the Centre

Intellectual disabilities are diagnosed by looking at two main things (The Qmrp, 2010). These are:

- the ability of a person's brain to learn, think, solve problems, and make sense of the world (called IQ or intellectual functioning); and
- whether the person has the skills he or she needs to live independently (called adaptive behaviour, or adaptive functioning).

Intellectual functioning, or IQ, is usually measured by a test called an IQ test. The average score is 100. People scoring below 70 to 75 are thought to have an intellectual disability. To measure adaptive behaviour, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behaviour. These are:

- daily living skills, such as getting dressed, going to the bathroom, and feeding one's self;
- communication skills, such as understanding what is said and being able to answer;
- social skills with peers, family members, adults, and others.

However, the severity of ID is classified by the following degrees of intellectual functioning:

- Borderline
- Mild
- Moderate
- Severe
- Profound

The centre does not have particular methods of identifying this group of children. The record shows that the children are often referred through the following:

i. Regular schools
ii. Doctors in the hospitals
iii. Neighbours
iv. Parents
v. Friends of the child's family
vi. Professionals

The child could also be identified based on the ages and stages of the children, as certain abilities and skills are expected to be performed by the children e.g. feeding, toileting, holding of spoon or pencils and so on. A number of standardized screening tools are available to screen children with ID. They vary in their sensitivity and specificity.

The method of screening in the centre does not differ from the ways they are identified, as there is no screening per- se. However, initial assessment is first carried out on the children and they are screened based on their characteristic traits.

5. Classification of children with Intellectual disabilities in the Centre

Classification of intellectual disability provides some clarity of severity of disability and the level of support that will be required in the educational system. In everyday life, children with motor problems or auditory or visual impairments might perform lower than their measured IQ would predict (Kerr, 2008). Similarly, receptive or expressive language or motor disabilities may result in IQ scores that underestimate their intellectual potential. Adaptive measures, typically assessed by interview, may vary depending on the

reliability of the informant. Typically, the definition of mental retardation requires that a child be below the population average by at least two standard deviations on measure of intelligence.

- *Borderline Intellectual Functioning* - IQ=67-85 (71-84, DSM-IV).
- *Mild MR* - IQ=52-68, ICD9 (50-55 to 70, DSM-IV)
    - Affected children are able to speak and to learn some social skills.
    - They can usually be expected to care for themselves as adults, with some guidance.
- *Moderate MR* - IQ=36-51, ICD9 (35-40 to 50-55, DSM-IV)
    - Affected children, although they are able to learn some language, usually have poor social skills. They will be able to achieve in school to about the elementary school level. Because their early motor milestones are usually attained in the normal range, children at this IQ level and above tend to be diagnosed around the preschool period. However, language development and achievement of activities of daily living and social skills are often delayed.
    - They will generally need complete supervision as an adult, often in a group home setting. They may be capable of unskilled occupations in a supported-employment setting.
- *Severe MR* - IQ=20-35, ICD-9 (20-25 to 35-40, DSM-IV)
    - Children with severe and profound MR are often diagnosed very early because acquisition of even the earliest motor milestones are delayed.
    - Affected children will be able to learn a few words and a few self-help skills, but will need a protected environment as an adult. A living situation in a group home with increased support will generally be possible.
- *Profound MR* - IQ=19 and below, ICD-9 (less than 20-25, DSM-IV)
    - Affected children will generally need full care as adults, often in a nursing home environment.

In the institution/ centre under study, it is the tradition to conduct initial assessment on every new intake to the school before classification. The result of the initial assessment based on the severity of their conditions, children identified with intellectual disabilities of ages 2 to 3 years receive early intervention in level 1. Other children identified are classified into various levels according to the severity of their conditions, regardless of their chronological ages. Those with mild and educable cases are classified to pre-vocational class to learn one skill or the other.

6. Intervention Strategies for Children with Intellectual disabilities in the Centre

A child with an intellectual disability can do well in school but is likely to need individualized help. For children up to age three, services are provided through an early intervention system. Professionals working with the child's family will develop what is known as an Individualised Education Programme (IEP), which will describe the child's unique needs. It also describes the services the child will receive to address those needs. It will also involve the service of the family, so that parents and other family members will know how to help their child with an intellectual disability.

Many children with intellectual disabilities need help with adaptive skills, which are skills needed to live, work, and play in the community. Teachers and parents can help a child work on these skills at both school and home. Some of these skills include:

- communicating with others;
- taking care of personal needs (dressing, bathing, going to the bathroom);
- health and safety;
- home living (helping to set the table, cleaning the house, or cooking dinner);

- social skills (manners, knowing the rules of conversation, getting along in a group, playing a game);
- reading, writing, and basic math; and
- as they get older, skills that will help them in the workplace.

The centre does not have rigid or must – use methods of intervention for children with ID. There are varieties of methods that work for the children. The centre considers the following as part of intervention strategies to meet the varying needs of children with ID:

i. The most important step in intervention is individualization. Individual Education Programme (IEP) is used in the centre, in which after assessment, attention are given to children on one-on-one basis
ii. Goals are set for each child based on their strengths and weaknesses and teachers work towards such goals.
iii. Low class-size is also adopted in the centre to enable the teachers have full control of instruction and management of the children.
iv. Task analysis is also applied in the centre. Skills are broken down to the children from simple to complex, and children are made to follow them. Every session of the task is role played to the children. Teachers show them the steps and stages and children are led to follow the tasks.
v. Children with ID also engage in vocational skills at least for the educable and those with mild case. Vocational skills available in the centre are: cooking, candle making, farming, hair braiding, block moulding etc.
vi. Children with severe case of ID are taught self-help skills/ daily living skills like brushing of teeth, washing of clothes, sweeping, wearing of clothes, tying of shoe laces and so on. Other children with profound case are taught sensory stimulation.
vii. Sports is another skill that children with ID engage in. Special Olympics becomes popular among the children in the centre as the centre is featuring athletes in various track and field events in local and regional Special Olympics Nigeria.

7. Parental Involvement for Children with Intellectual disabilities in the Centre

Parents' reactions to intellectual disability are very inconsistent but tend to follow a similar pattern. It is normal for the parents to feel sad about the loss of the 'normal' child while at the same time having to come to terms with disability, both emotionally and practically (Jacques 2003; Banks 2003). Most families show flexibility and common sense as well as experiencing emotional pain and stress. Most families will be familiar with, if a coping strategy is ineffective and change their approach. However, a small number will adapt in ways that can lead to problems, such as conflict with spouse, external agencies, rejection, leading to inappropriate care for their child.

Even with the above, families of most students with disabilities are very involved in supporting their children's educational development at home. Most families report regularly talking with their children about school and helping with homework. Children with disabilities are more likely to receive help with homework than are their peers in the general population. The difference in homework support is especially apparent for those who receive frequent help: students with disabilities are five times as likely as their peers in the general population to receive homework assistance frequently.

The parental involvement in the area of social and academic affairs of the children in the centre is in two sides. The first side of parental involvement is that some parents are seriously involved in attending to their children's needs as requested by the school management. Parents assist their children in home work at home. They often find out how their children are fairing and always eager to know the progress their children are making in the class/ school. Some show interests and attend "Open Day" organized by the school to interact with their children and teachers. Prompt payment of school fees is another involvement the centre considers as contributions parents are making to the progress of their children.

On the other hand, some parents are quite opposite of the above, as they see the centre as 'dumping ground', where their children could be dumped. They do not care about the progress their children are making in the centre, and do not attend meetings organized by the centre's management. This group of parents often times expect miracle or magic on their children from the centre or teachers.

8. Implication for Homes, Schools and Society

Intellectual disabilities (ID) is one of the most distressing handicaps in any society. Development of an individual with mental retardation depends on the type and extent of the underlying disorder, the associated disabilities, environmental factors, psychological factors, cognitive abilities and comorbid psychopathological conditions. Social development means acquisition of the ability to behave in accordance with social expectations. Becoming socialized involves three processes: i) learning to behave in socially approved ways, ii) playing approved social roles and iii) development of social attitudes. For people with intellectual disabilities, their eventual level of social development has implication for the degree of support needed in their literacy arrangement and their integration in the community with increasing emphasis on mainstreaming the attainment of skills in personal, domestic and community functioning. It also contributes considerably to quality of life.

Kumar, Singh and Akhtar (2009) opined that children with intellectual disabilities, due to low intellectual growth, function with a limited capacity in comparison to normal children. Hence the social functioning of these children is found to be affected, and this is closely related to degree of impairment. As the degree of impairment in terms of intelligence goes down, it is observed that the child approaches an average or satisfactory level of social functioning. They also found that the level of social development varies with the intellectual level among persons with mental retardation, or a wide range of family and environmental variables may also influence social development.

Parents of students with disabilities share the concerns about child-rearing and about education and also have additional concerns related to their children's disabilities. With this, it is important for the teachers to respect these very real and serious parental concerns. Teachers can serve an important role in, on one hand, reassuring and educating parents regarding measures taken at school to ensure children's safety and, on the other hand, alerting school officials to safety concerns that need attention. An additional important role for school teachers working with parents of students with ID is to encourage parents to help their children develop independence by not overprotecting them. Although making such adjustments may be difficult for parents, they can be helped to see that fostering independence is in the long-term best interests of the child.

Despite the movement toward classroom inclusion, many classmates without disabilities may have had little or no exposure to people with ID. The former may be curious or fearful or rejecting or respond in other ways. The school or teachers have a role to play in the education of all students about disabilities in general and about a classmate's disability in particular. Friendships play an important role in the life of the developing child. Relationships with peers play an integral role in adolescents' identity formation. All parents want their children to have friends. Parents of children with disabilities may be particularly concerned about their children's abilities to make and keep friends.

Parents of children with disabilities may have concerns about the content of the information being presented to their child's peers about disabilities or about the manner in which it is presented. It is respectful and appropriate to include parents in this decision; the best approach is also to give the parents themselves voice in their children's matter. The school should take care not to violate the confidentiality of individual students in such presentations.

Finally, teachers may want to invite parents of children with ID and students with ID themselves to be part of their educational efforts. Parents and/or students may be interested in making inputs to classes, teachers, or groups of parents. Often, such inputs, speaking from personal experience, are particularly effective educators.

9. Conclusion

The primary goal of education for this group is to increase independence by teaching functional academics, social and other skills needed in everyday life across home, school and community, depending on the student's abilities (conceptual, social, and practical), needs for support and school placement, the educational focus and methods will vary. The socioeconomic level of the community influences the quality of special education and the amount of support an individual receives in school and during adult life.

In assessing children with intellectual disabilities, it is important to identify the nature and extent of any learning difficulties and to refer for psychometric assessment if necessary. If the extent of the intellectual disability has not been identified, the child can be put under demands and close monitoring. It is important to note that the family's and teachers' expectations are at the right level; they should understand that the child will continue to learn and progress, albeit at a slower rate than their developing peers, and will still be able to achieve a great deal. It should be explained that, because of the slower rate of learning, the gap between the child and the developing peers will broaden in terms of intellectual ability although in other areas of life the child will have similar aspirations and will want a similar way of life.

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