Review Article

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Achieving Developmental Milestones: The Experience of Parents of Children with Developmental Disabilities (Autism)

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Abstract

Developmental disabilities (DDs) refer to a group of conditions that influence the early development of children and cause changes in their normal developmental pattern affecting their physical, language and mental abilities. Autism which is an example of DDs is the most frequently diagnosed globally; Cameroon inclusive. In fact, its prevalence is on the rise due to awareness and improved methods of diagnosis. Children with autism do not achieve developmental milestones as typically developing children do and as such might face difficulties transiting from youth to adulthood. As a result, parents of these children go through stressful moments especially in settings where the necessary treatment and support systems are not available. This paper presents parents' experiences regarding the attainment of developmental milestones by children with autism, transition to adulthood, treatment approaches and support options.

Keywords: Developmental Disabilities, Children with Autism, Developmental Milestones, Parents, Transition, Treatment Approaches, Support Options

Introduction

Children with developmental disabilities such as autism have biologically based deficits of the brain that manifest shortly after birth. Therefore, the achievement of specific milestones during the stages of development can present unique challenges for a child with a developmental disability especially autism. Autism is a pervasive neurodevelopmental disorder manifested as impairments in social communication and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association [1]. These children experience functional impairments over their lifespan [2] leading to stress and extensive economic impact on their families [3]. Also, the quality of health care children with developmental disabilities receive is sub-optimal [4], this and other social factors can have a detrimental effect on the physical and mental health of mothers and fathers of these children. The paper sought to:

1. Critically analyze the experience of parents of persons with a disability.
2. Explore issues with transition from youth to adult life for persons with disabilities, particularly those with developmental disabilities.
3. Critically examine various treatment approaches and support options for individuals with developmental disabilities particularly those with autism.

Parents' Experience Regarding the Attainment of Developmental Milestones

Infancy: Many developmental processes in infancy function to strengthen the attainment of developmental milestones like smiling, head control, cooing and other vocalizations. However, these are usually delayed or nonexistent in children with disabilities [5]. Also, there is delay in motor coordination and the ability to explore the environment. These often lead to anger, frustration and sorrow in parents who are unable to comprehend what is going on in their children.

Early Childhood: Generally, it is during this period that many children with disabilities are identified and language development is usually delayed in persons with autism. Many parents are distressed in response to the news that their child has a disability [6]. These children due to language difficulties resort to disruptive, aggressive, or self-injurious behavior out of frustration due to not being able to communicate needs or desires. Therefore, parents are emotionally disturbed and do not know what to expect. Also, self-care skills are frequently delayed; these children may be unable to effectively take part in activities of daily living such as eating, dressing, and toileting among others. This may lead to continuous conflict between parents and their children.

Childhood: With regards to physical development parents may recognize that at preschool age their child lags behind typical peers or when compared to his/her siblings in skills like walking or climbing stairs or kicking a ball. Hence, they may seek information in order to assist the child improve skills development. However, parents go through a combination of feelings like shock, denial, disbelief, guilt, and a sense of loss.

Talking about cognitive development in their children some parents may notice behaviors that are either below or significantly above typical peer levels. This includes the ability to think, learn and solve problems. But some children with a developmental disability like autism may not be able to explore the world around them appropriately and learn normally while others may perform exceptionally. Whatever the case may be parents seek for information in order to meet the needs of their children since special services are mandatory during this period [7].

Concerning social development, parents may observe poor or lack of eye contact, poor interaction with peers or attachment to objects like in the case of autism. Also, parents having children with disabilities will notice their child trails their peers in the development of age-appropriate adaptive life skills like toileting or lace their shoes. Furthermore, the child may be unable to express and control feelings. For example, the child is unable to request for assistance or show and express feelings or may manifest abnormal behaviors, and is unable to create friendships. These will always make them to seek help to close deficit gaps for their child. Parents will seek help in order to manage the child’s early challenging or unusual behaviors [8].

Parents’ Experience with Respect to Health Care and Other Special Needs Support

The health care and educational needs of a child with disability are particular areas of concern to parents. Parents having children with disabilities tend to seek and access multiple sources of information regarding their child's health and behavior since the child experience higher health care needs [9]. However, some parents may be unable to find the necessary support especially those in developing countries due to lack of availability. A social support network is essential to assist parents in developing effective strategies for coping with difficulties. This network can be family and non-family which includes friends, neighbors, religious groups, school, community, network of parents, health team and public policies that support family assistance programs [10]. For instance, support programs for parents and families of children with autism such as online blogs are used as strategy to reduce maternal stress and improve the quality of the mother-child relationship. This practice works as a distributor of stress; sharing by writing can improve emotional adaptation when a person is faced with stressful life events and in turn significantly improve psychological well-being. [11] found that the benefit of meeting other parents through such programs makes parents not to feel like they are alone out there. Also, they acquire professional knowledge; new approaches and practices in their daily lives.

It is worth mentioning that some parents, especially those in resource limited nations experience lack of applicable and relevant educational resources (e.g schools, teachers,learning materials etc) and support for their children with autism [12]. Few schools are available to accommodate children with autism, as a result most children with autism do not attend school. The parents are faced with the responsibility of educating or training their children. This is challenging especially to the mothers as they have to devote almost all their time caring for them. Hence, they suffer physical problems such as exhaustion, sleep disturbance, and loss of appetite. In addition, mothers face emotional problems like denial during early diagnostic phase. They suffer anxiety regarding child's future, and are upset due to the child's disability. Acharya and Sharma [13] reported mothers were worried that they did not really know what the future would bring for their child. They hoped that their child could have a “normal” life or could acquire some skill to live an independent life. Hence, parents experience emotional and psychological pain especially on diagnosis.

Generally, after the diagnosis has been made, the health team, nurses in particular, are expected to counsel the parents, tell them what to expect, educate them on how to interact with the child [14, 15]. But in countries where children with disabilities may have poorer access to health and educational services, parents and family members struggle to manage the disabilities in their own way.

Parents’ Experience with Regards to Family Relationships and Friends

On a positive note, parents and siblings of children with disabilities usually cherish and pay much attention to their loved ones having disabilities, and as such caregivers may acquire many new skills and abilities in the course of performing their caring roles [16]. For instance, parents of children with autism may learn different ways of improving their child’s speech and social interaction. However, siblings of children with disabilities may feel neglected and not loved because parents mobilize all energy and resources towards the care of the child with disability. Also, some siblings may even drop out of school either because of limited funds or in order to assist their parents render proper care to the child with disability.

On the contrary, research has revealed that parents of children with disabilities experienced a less secured couple relationship compared to parents with typical children. Some parents were unable to maintain a stable couple relationship. Also, parents having children with disabilities may experience a lower level of mental wellbeing and a higher level of stress than parents without children with disabilities; women in particular are at a higher risk for depression. In a study by Acharya and Sharma mothers expressed a sense of feeling isolated as they were unable to participate in social activities because they devoted most of their time to the care of their children with autism. They thought it was deemed inappropriate to take them to religious ceremonies and other gatherings due to their antisocial behavior. Mothers reported that they were scolded by family and others and blamed for their child's disability.

Furthermore, according to mothers' people in the community were more sensitive to the behaviors of children with autism and said mother's behaviors and personalities are the potential causes of autism Acharya and Sharma. Overall, parents having children with disabilities experience more challenging parent-child relationship and higher parenting stress compared to parents having typical developing children. Thus, having a child with a disability can lead to social, emotional or behavioral problems.

Transition from Youth to Adult Life for Persons with Developmental Disabilities

Literature shows that children with disabilities face challenges in taking part in many activities and transiting from one level to another. For instance, they have difficulties beginning school as well as moving from one level of education to another. Also, the overall quality of the educational experiences of children with disabilities at any point in time is often poor [17] making it difficult for them to transit from one level to another. Transition is particularly difficult or challenging for children with autism. However, planning can make the difference between a successful transition or a stressful situation for both the teens on the autism spectrum and their parents. It starts occurring at about the age of 12 years and continue into adulthood where body changes due to hormones and environment amongst other factors.

Transitions usually symbolize alterations in expectations with respect to a person's cognitive and adaptive functioning and the social roles they assume as they grow old. Transitions for teens with developmental disabilities (DD) can be especially challenging because when teens turn 18, they are expected to make decisions related to medical, financial and other aspects of their lives on their own, or at least contribute to these. This paper looks at transitions as developmental and systems issues.

Transitions as a Developmental Issue

Literature reveals that children with developmental disabilities (DD) generally experience substantial physical and mental health problems during transitions, this is particularly exaggerated for children with autism. These problems are often as a result of changes in familiar environments, social circles, and the nature and level of supports [18]. Therefore, a child with a DD just like a typical child needs to be prepared for transition in order to ensure proper transition in the different areas of their lives especially, health care and supportive services. Hence, when this preparation involves a child with a DD it needs a collaborative effort. This includes the child's family, school, health care providers and public service agencies among others. All must work as one to mobilize and direct resources towards a successful transition to adulthood.

Therefore, the different professionals involved need to consider the emotional, behavioral, social, and spiritual difficulties that go with transitions for an individual having a DD. As this will go a long way to avoid and address these related health and social problems and ensure a successful transition. A successful adult life normally entails living independently, being employed and engaged in interpersonal and intimate relationships. It is worth mentioning that the planning process for transition should be directed towards the needs of the individual and takes into consideration the person's distinct abilities and difficulties.

Transition plans should provide information about community-based services and support, social security income, and affordable housing options. All information about transition services and evidence of the benefits related to transition service systems should be communicated in clear language to parents. This will ensure a successful transition and in turn enhance the individual's employment ability, continuing education options, housing options, and have a meaningful life that continues after school. Where the transition is successful the individual with developmental disabilities (DD) is able to live an independent life and be respected like other members of their society.

However, some persons with mild disability may require intermittent supports and periodic assistance, especially when experiencing social or economic stress. On the other hand, where the transition is not successful because of severity of the impairment, adequate support is provided to the family to ensure that proper assistance is given during transition and in the next phase of life.

It is worthy of note that the family of an adolescent who is in transition is expected to adjust and adapt to the needs of the person with DD transiting to the next level. This is because the family will always go through similar difficult situations as their child with the DD. Hence, the successful transition of an adolescent with DD to an adult life has a lot to do with the general well-being of his or her family, especially mothers, who adopt new roles as caregivers. Also, family caregivers find it challenging to continuously render high levels of care to their child who has become an adult [19]. Therefore, during the transition period family caregivers are expected to receive support from family physicians on how to continue their caregiver's roles.

Transitions as a Systems Issue

It is worth mentioning that in addition to addressing individual and family issues when a youth is transiting to adulthood, the continuity and appropriateness of support systems should also be addressed. Therefore, the physicians directly concern with the care of the child together with other professionals should work proactively to identify needs ahead of the transition, and to assign responsibilities for managing, piloting and integrating health care. Hence, planning for the transition process should commence as early as between 12 and 16 years. This gives enough time to develop a transition plan which is done preferably during the relatively stable phase of adolescent school life. Also, this allows enough time for certain aspects of this plan, for example, the development of relevant skills for adulthood to be implemented. Other necessary aspects of the transition plan include vocational and social issues such as inclusive postsecondary education, supported employment and living, and social-leisure-community engagement.

The transition plans should be comprehensive in scope and highlights skills and supports that the child with developmental disabilities and his/her family will need during the early adult phase of life. This plan should be continuously reviewed and updated to ensure its effectiveness.

Treatment Approaches and Support Options for Individuals with Developmental Disabilities

The most important treatment approach for children with developmental disabilities comprises a multidisciplinary effort directed at many aspects of the child's life. These include education, social and behavioral problems including support for family caregivers. In the following paragraphs the different components of the treatment approach are scrutinized.

Educational Support

Education is the most important component in the intervention for children with developmental disabilities and their families. For an educational program to achieve it aims it must be developed in line with the child's needs and should address the child's unique strengths and difficulties as well as the family needs. This is because the child's developmental level and his or her eligibility for support as well as goals for independence provide a foundation for developing an individualized family service plan (IFSP) or an individualized education program (IEP) [20]. Also, it should be noted that the family always included in the plan because the child's learning starts at home usually between the ages three to four years. Periodically a review of health status and ability to function at home, at school, and in other social contexts is done. Again, the child is reevaluated whenever he/she is not performing as expected, or when moving from one service provision system to another. Furthermore, reevaluations are done during early childhood and preschool years to ensure that the program meets the child needs as he/she grows up.

Social and Behavioral Support

At the age of five years, formal special education services are provided when most children are introduced to a more formal learning environment at school. Additionally, the child's physical, social, and recreational needs are to be attended to. This will enable the child to socialize and take part in recreational activities with typically developing children. This goes a long way to enhance his/her social-emotional development and builds resilience, which in turn can influence the child's achievements later on in life. In addition, they should be allowed to participate comfortably in mainstream health promotion activities, as well as socializations and sex education. Also, appropriate sport support services are expected to be made available to enhance inclusion and encourage participation in sports or related exercise regimens.

Furthermore, social activities which are age-appropriate and match the child's behavior, as well as opportunities for enhancing social-emotional independence are mandatory. These may include family or school trips, socialization in school clubs and school dances among others. These improve the physical, social and emotional health and development of the individual with developmental disabilities. Above all, activities that enhance the development of problem-solving skills such as exposure to new experiences should not be left out.

Talking about behavioral support, behavior therapy during this phase is necessary to ensure that children with developmental disabilities especially those with autism and attention-deficit/hyperactivity disorder (ADHD) are not bullied in the school or recreational environments [21]. This is in order to facilitate the child's socialization and while exposing him/her to sufficient academic opportunities. It is worth mentioning that behavior problems may also be as a result of unrealistic parental expectations and difficulties encountered at school [22].

Furthermore, literature shows that challenging behaviours such as aggression, self-injury and tantrums often represent attempts by the children with autism to communicate, gain attention, or avoid frustration [23]. Therefore, before intervention the abnormal behavior is assessed taking into consideration the child's cognitive age first, and then the chronological age in order to evaluate the said behavior in the environmental context of the child's functioning. For some children needing intervention, simply, a change of environment such as modifying the classroom environment, may improve behavior. While others may require behavior management techniques and/or the administration of certain therapies like psychotropic medications.

However, before a long-term therapy with any medication is instituted, a short trial is carried out, and its use is reevaluated at least every year to determine when the treatment can be discontinued. Other therapies required for children with developmental disabilities are physical therapy, occupational therapy, speech-language therapy and behavioral therapy among others. In order to ensure positive treatment outcomes, the individual should be properly assessed and proper treatment administered followed by adequate monitoring and reassessment. This will in turn prevent challenges in the home, neighborhood or school environment which may occur if the individual was not properly identified and treated.

Family Counseling and Support

All families having children with developmental disabilities are given anticipatory guidance regarding their child's health and development [24]. This is to prepare them psychologically so that they can cope with their child's diagnosis especially those having children with severe disabilities. It should be noted that family counseling is an essential part of the treatment plan of children from families where they find it difficult to come to terms with their child's condition. In such cases family counseling is also a vital part of the continuous re-evaluation.

Since the needs of this special group of children and their families change with time, it is important that their health, learning, adaptive, and behavioral goals are reassessed and adjust developmentally and school-related programming needs accordingly [25-28].

Conclusion

Human development is a complex process of change and maturation from birth to death. Typical development in children can be used as a measure to compare the advancement of same-age children. This is very important because the kind of experiences children have during the early stages of development determine how well they will interact and integrate in society.

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