

## **ABSTRACT**

### **A COMMUNITY BASED REHABILITATION SERVICE AND FOOD - RELATED PROBLEMS OF PARENTS/CAREGIVERS OF CHILDREN WITH DISABILITIES**

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Community based rehabilitation is a concept first documented by WHO in 1979 which covers all disabilities and all age groups. It places the responsibility for service delivery on the family and is administered by a health infrastructure. In other words it is a service which includes older persons as well as children with all types of disability, provided in the community by the community.

The 3D Projects Limited is the first fully established community based rehabilitation programme in Jamaica which has been in operation since 1980. The programme is unique in that it utilizes local resources within the community, and low cost methods in meeting the needs of the disabled in the community.

The study aimed to determine how a community based rehabilitation service is meeting the nutritional needs of parents/caregivers of children with cerebral palsy.

All parents/caregivers of children with cerebral palsy enrolled in the 3D Projects programme and the community rehabilitation workers within the four urban areas in the parish of St. Catherine were included in the study.

Data were collected by focus group discussions and self-administered questionnaires in three of the 3D Projects Limited facilities in the parish of St. Catherine. The sample consisted of 55 participants of which 40 were parents/caregivers (1 male and 39 females), and 15 community rehabilitation workers (1 male and 14 females) participated in the study. Parents/caregivers ranged from 18-60 years.

Data were coded and analyzed manually, as well as in Epi Info Version 6, a statistical package for analysis of epidemiological data.

Mean nutrition knowledge scores were slightly higher for CRWs than parents/caregivers. Using the correlation coefficient there was no correlation between mean nutrition knowledge score and age for both groups. However, when the t-test was used to compare mean nutrition knowledge score and gender, education and occupation for both groups no significant differences were observed. Using the Fisher's exact test, no association was found among the first five common food related problems: constipation, inadequate amount of food, underweight, inability to chew and swallowing/gagging as identified by the parents/caregivers and CRWs. However, other common problems observed by the CRWs such as bottle feed only, poor positioning, drinking only and financial were

found to be highly significant. Among the strategies used by the parents/caregivers and CRWs in solving the common food related problems many differences were observed.

More than half of the children at the time of the study were on liquid or crushed diets, medication and had other health problems. CRWs training provided basic nutrition information to work and assist parents/caregivers whose children have minor feeding problems, but little guidance on how to meet their nutritional needs. Many parents/caregivers felt that the programme met their food related needs partially approximately 42.5% and not at all 30%, while they indicated that their non-food related needs were met fully.

Overall, the nutrition component in the 3D Projects Limited programme and the content in the CRWs training course is weak and needs to be strengthened. Nutrition education and intervention should be an integral part of the 3D programme especially for children with multiple disabilities. Such topics should include portion control, adjustment of food texture and consistency, low cost menu planning, diet therapy, food preparation, storage and sanitation.