A Framework for Healthcare Provision to Children with Intellectual Disability

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ABSTRACT

Purpose: *The Kudumbashree mission, an initiative of the Government of Kerala state in India, has collaborated with Local Self Governments to set up 'Buds', a special school system for individuals with intellectual disability. The objectives of this study were to evaluate the structure and functioning of 'Buds' schools, to identify the healthcare needs of the students, and to conceptualise a framework for healthcare provision.*

Method: *A cross-sectional survey was conducted among 202 children at 11 registered 'Buds' schools in Kerala. A multidisciplinary team consisting of a psychiatrist, public health personnel and a social worker from the Medical Colleges of Kerala, visited the institutions. Data collection consisted of abstraction from medical records, interviews with parents, and clinical assessment and prescription of intervention by the specialists concerned. A pre-tested semi-structured questionnaire was used for every child. Using both quantitative and qualitative techniques, the public health personnel in the team evaluated the structure and functioning of the schools.*

Results: *The most commonly associated condition was epilepsy, seen in 11.9% of the children, while 28.2% had behavioural problems. The medicines needed were mainly anti-epileptics and drugs for behavioural problems. Interventions for self help and social skill training were also among the important requirements. The infrastructure and other facilities were poor in many schools, with the average student to teacher ratio at 14:1. While these institutions were well utilised, functioning was good only in 27.2% of the schools. Healthcare services and visits by healthcare personnel were far from adequate. This study proposes a framework in which the Medical Colleges and Health Services can function together to deliver healthcare services to children at these schools, with linkages from the District Mental Health Programme (DMHP).*

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Conclusion and Recommendation: *Evidence that these schools are well utilised indicates a need to propagate this initiative in other areas of the state, country and other countries. However, improvements in infrastructure, human resources and other logistics are required. Besides, the healthcare needs of these children have to be addressed. A comprehensive healthcare programme through the existing system, using a multidisciplinary approach, needs to be developed.*

Key words: *Local Self Government, community based rehabilitation, Primary Health Centre, intellectual disability.*

INTRODUCTION

Intellectual disability is a characterised by significantly sub-average intellectual functioning (an Intelligence Quotient score under 70), with onset before the age of 18 and concurrent deficits in adaptive functioning (American Psychiatric Association, 2000). Prevalence of intellectual disability in the general population varies from 0.3% to 3% (Satapathy et al, 1985). The vast majority of children, if given adequate support, can go on to live productive and fulfilling adult lives. The Persons with Disability Act 1995 in India, envisages free and compulsory education for persons with disability in the age group of 6-18 years, in addition to the protection of their rights. In spite of the general recognition of their associated healthcare needs, very little effort has been made to devise new and more effective systems to provide them medical care. This is due to a deficient understanding of the true nature and occurrence of these conditions, as well as the possibilities for preventing and correcting them, and the implications that correction has for the child's overall progress and prognosis (Smith et al, 1969).

In Kerala, institutions for persons with intellectual disability were managed mainly by missionaries, Non-Government Organisations (NGOs) and private agencies. Often the poorer sections of society tend to be excluded and unable to benefit from them. Hence the Kudumbashree mission facilitated a special school system named "Buds", at Venganoor grama panchayat of Thiruvananthapuram district (Grama panchayat is the lowest in the three-tier system of Local Self Government in India).

The Kudumbashree mission is an innovative model of poverty alleviation through women's empowerment. It was launched by the Government of Kerala in 1998, through concerted community action under the leadership of Local Self Governments (LSGs). The links between poverty and any disability are twofold –

not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability (Elwan, 1999). It is usually the women of these families who bear the brunt of the problem. When the Kudumbashree mission staff worked in Venganoor grama panchayat, they were made aware of the problems faced by poor families who had children with intellectual and physical disabilities. It sowed the seeds of an idea: to set up a special school named 'Buds', for the benefit of these children in the panchayat. Subsequently, 10 other panchayats followed suit and started "Buds" schools (Government of Kerala, 2007).

The ownership of the schools rests with the respective grama panchayat but the Kudumbashree mission acts as a facilitator, coordinating the functioning of the schools with other agencies involved in the project. Kudumbashree also helps in raising funds for the schools, apart from the budgetary allocation by the respective grama panchayat (Unnithan, 2009). As the Local Self Government Institutions (LSGI) were empowered to initiate and support rehabilitation activities for persons with intellectual disability, Kudumbashree proposed to develop these 'Buds' schools as model institutions for other LSGI in the state. The Department of Community Medicine at the Thiruvananthapuram Medical College was requested to submit a professional assessment of these schools and to develop a project for healthcare delivery so that these needs could also be met.

This paper highlights the findings regarding the healthcare needs of children in 'Buds' schools. It also evaluates the structure and functioning of these schools, and tries to conceptualise a framework for provision of healthcare through the existing health system.

METHOD

A cross-sectional survey was conducted among 202 children at 11 registered 'Buds' schools in Kerala. A multidisciplinary team from the Medical Colleges of Kerala, consisting of a psychiatrist, public health personnel and a social worker, visited the institutions. Data collection was done by abstraction from medical records, interviews with the parents, and clinical assessment and prescription of intervention by a psychiatrist. A pre-tested semi-structured questionnaire was used for every child. All the persons involved in data collection were trained uniformly for assessment. The variables assessed included socio-demographic (age, sex) data and extent of disability, problems other than intellectual disability and healthcare requirements. The final diagnosis was made on 5 axes, namely, axis

1: severity of intellectual disability (IQ); axis 2: possible aetiology (any treatable causes); axis 3: associated medical problems (Epilepsy, Cerebral Palsy, Visual/ Hearing impairment, Feeding/Sleeping problems); axis 4: associated psychiatric/ behavioural problems; axis 5: family and psychosocial factors – impression regarding parents' perception, knowledge, expectation and attitude.

A public health personnel and a social scientist evaluated the structure and functioning of the schools. A questionnaire with four parts was used, namely, assessment of resources, function, summary sheet of children and staff details. The assessment of infrastructure and human resources available in the schools was based on the criteria outlined in Government Order 148/09/LSGD dated 29-07-2007, which stipulates the requirements for these schools. There were in-depth interviews with teachers, to elicit the problems faced and suggestions for improvement. The utilisation of the schools was assessed by taking the minimum and maximum recorded attendance in each school. The functional level of schools was assessed using 10 parameters and graded as poor, satisfactory and good. The parameters used were maintenance of records, educational services, medical care and services, availability of specialist services, school neatness, utilisation by children, parental involvement, motivational level of teachers, community participation and involvement of local legislators. The maximum score that could be attained was 20. The scores of individual schools were calculated as a percentage of the maximum score. Schools that scored above 70% were categorised as ones with a good level of functioning. Scores between 30%-69% were indicative of satisfactory functioning and scores less than 30 % were considered as poor functioning. Analysis was done using Statistical Package for Social Sciences (SPSS) version II. The results are described as simple percentages with 95% confidence intervals.

Permission from the concerned authorities and institutions was obtained, and the visiting dates were scheduled by prior appointments. Confidentiality of information given by the participants and institutions was maintained throughout the study.

RESULTS

Of the 202 children examined, 84 were female (41.6%) and 118 were male (58.4%). The youngest child was 4 years old and there were 2 individuals who were above 40 years (Table1).

Table 1: Age distribution of Study Participants

Age group	Frequency (N=202)	%
<10 yrs	39	19.3
10-20 yrs	117	57.9
20-30 yrs	35	17.3
30-40 yrs	9	4.5
>40 yrs	2	1.0

The types of disability among children are summarised in Table 2. Intellectual disability was most common, followed by multiple disabilities.

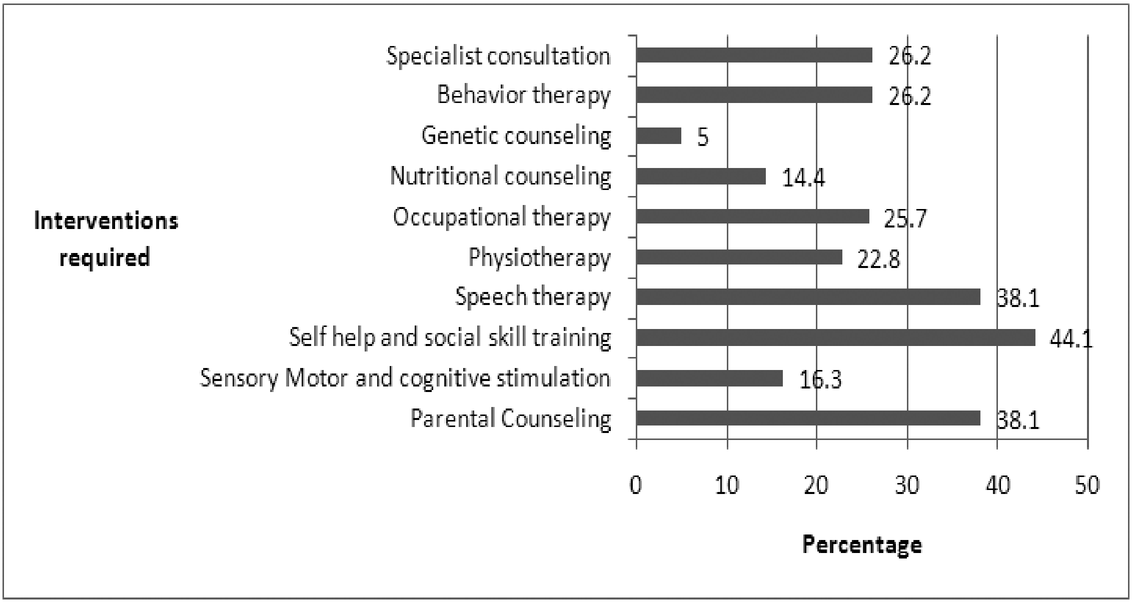
Table 2: Type of Conditions and their severity

Variable	Categories	Frequency N=202	% (95%CI)
Type of disability	Intellectual disability	124	61.4(54.7-68.1)
	Multiple disability	36	17.8(12.5-23.1)
	Autism	8	4.0(1.3-6.7)
	Cerebral Palsy(CP)	12	5.9(2.7-9.1)
	Any other	22	10.9(6.6-15.2)
Other disabilities	Vision	32	15.8(10.7-20.8)
	Hearing	17	8.4(4.5-12.2)
	Locomotion	70	34.7(28.1-41.3)
	Epilepsy	24	11.9(7.4-16.4)
	Behavioural problems	57	28.2(21.9-34.4)
Assessment of disability by Medical Board	<40%	16	7.9(4.1-11.6)
	40-60%	67	33.2 (26.7-39.7)
	60-80%	27	13.4(8.7-18.1)
	>80%	21	10.4(6.2-14.6)
	Not done/Not available	71	35.1(28.5-41.7)

The aetiology of the disability in 29.2% (59/202) of the children was birth-related trauma or other causes during the mother's pregnancy, 11.8% (24/202) had genetic causes and the causes were not known among 58.9% (119/202). These children also had other conditions, the most common ones being locomotor and behavioural problems (Table 2). A few children had feeding problems and heart disease. As per the medical board's assessment, 6 children had 100 % disability. Parents were the caregivers for most of the children. Other caregivers included brothers, sisters and grandparents.

The various intervention requirements were assessed and are summarised in Figure 1.

Figure 1: Interventions required



Interventions for self-help and social skills training were perceived to be the most important requirements, along with speech therapy, physiotherapy and occupational therapy. The medicines needed were mainly anti-epileptics and drugs for behavioural problems.

The physical infrastructure of the schools was assessed as per the recommended criteria, and the major findings are presented in Table 3.

On a list of 147 items, which included furniture and indoor equipment, it was found that less than 10 items (7.04%) were available in these schools. Only 25% of the teachers (4 /16) had a Rehabilitation Council of India (RCI) registration. The average student to teacher ratio was 14:1. The training received by the teachers was heterogeneous in terms of duration, content, place and quality. The major source of funding for the schools came from the Grama panchayats. In some instances, higher administrative levels at the Block panchayat and District panchayat had contributed towards the construction of the school building and purchase of the vehicle.

Table 3: Physical Infrastructure and other Facilities of Schools

Physical infrastructure &other facilities	Number of schools (%)
Adequate land area (15 cents)	2 (18.2)
Own building	8 (72.7)
No. of rooms adequate	3 (27.2%)
Adequate water supply	10(90.9)
Sanitation adequate	9 (81.8)
Separate toilets for boys and girls	2 (18.2)
Transportation facility for students	9 (81.8)
Playground available	3 (27.2%)
School accessible*	9 (81.8)
Safe for children	9 (81.8)
Total	**11 (100)**

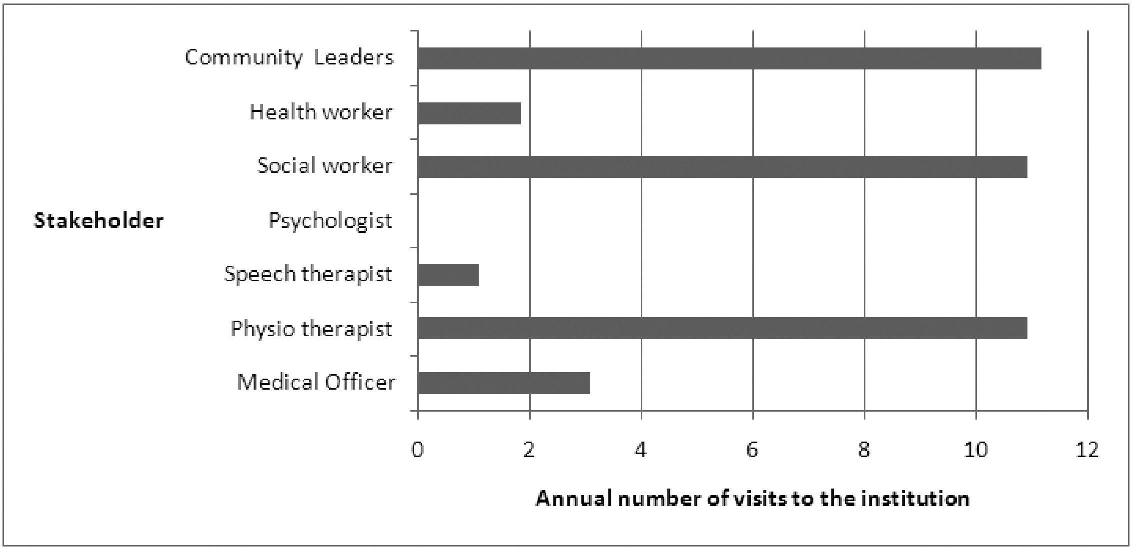
*Accessibility was assessed by the presence of a public conveyance facility within 15mts walking distance.

The children were trained mainly in areas of communication, motor development, functional development, social skills, academics and in activities of daily living. There were not enough books available and no vocational training was imparted. While community leaders paid frequent visits to most schools, involvement of parents in child care was minimal. The minimum recorded attendance in the individual schools ranged from 54% to as high as 86%, and the maximum recorded attendance ranged from 62.5% to 100%.

The annual average frequency of visits by health professionals and community leaders is shown in Figure 2.

Functioning was good in 3 of the 11 schools (27.2%), satisfactory in 5 (45.5%) and poor in 3 (27.2%), based on the total score of the functional parameters assessed. Least scores were obtained for availability of medical care and availability of specialist services.

Figure 2: Annual frequency of Visits by different Stakeholders



DISCUSSION

Despite the global emphasis on mainstreaming and normalisation, both nationally and internationally, most community healthcare systems are unprepared to meet the health needs of individuals with intellectual disability (Horwitz et al, 2000). Unfortunately most people in positions of authority do not have precise information on which to base effective action. This study was an attempt in this direction.

The sex distribution in favour of males obtained in the study is comparable with other studies on children with intellectual disability (Chakrabarti & Aryal, 2003; Kaur et al, 2006). This could be due to a wider range of spectrum of intelligence in males (Deary, 2007). Over half of the children are in the second decade of life, which is also in agreement with another study from South East Asia (Ghising et al, 2008). Therefore, catering to the health needs of adolescents, especially female children, should be a priority for health programme managers of such institutions. Other literature also reveals that there are people in the extremes of age range in these institutions (Deary, 2007). This points to a need for similar institutions for all age groups, as it becomes difficult to set age limits for admission. Healthcare programmes for these schools should therefore adopt an entire life course approach.

Most studies agree on the prevalence of cerebral palsy at 2 to 3 per 1000 live births (Winter, 2002). Locomotor problems were found in 35% of the children in this study, compared to 17% in another study (Smith et al, 1969). Visual abnormalities in children with intellectual disability are well documented (Smith et al, 1969; Karjalainen et al, 1983). Hearing impairment was perhaps underestimated in this study when compared to other studies which used more sophisticated methods (Karjalainen et al, 1983). The requirements of physiotherapy and speech therapy are high when compared to a study done elsewhere (Smith et al, 1969). Incidence of epilepsy in the general population is estimated at 1.7% -2.5%. A prospective cohort study showed that by the age of 22 years, 15 % of children with intellectual disability had epilepsy (Steffenburg et al, 1995). This is at par with the findings of this study. While behavioural problems were identified in 28% of the children, a similar study from the US found it to be 17% (Smith et al, 1969). The aetiology of the disability was not known in more than half of the children in this study, which is in keeping with earlier reports on aetiological diagnosis of intellectual disability (Ghising et al, 2008).

The findings and inferences highlight the problems which need to be addressed while planning a healthcare programme for these schools. Although the schools are definitely a boon to the community, as evidenced by the high utilisation, there are major deficiencies in infrastructure and human resources. In view of the shortage of staff, mothers of children/ volunteers/ retired personnel could be trained as teachers. This study may enable policy makers to estimate the number of personnel required for the different disciplines and may provide pointers to the areas where resources should be improved.

Inclusive education is being promoted in order to give every intellectually deprived child access to education, but such children do have problems in attending normal schools. Adjustment problems, and learning and understanding difficulties make them fail repeatedly and lose confidence (Obaseki et al, 2009). Schools with day-care facilities reap the advantages of both institutionalisation and de-institutionalisation approaches. ‘Buds’ schools in Kerala are a model of these types of schools.

The ‘Buds’ schools can also be regarded as institutions that help in the realisation of community based rehabilitation principles. Providing adequate healthcare to the children of these schools is essential to the success of this model. Therefore this Local Self Government Initiative which is sustainable, community based and ensures equity, needs to be replicated across the state and the nation with an inbuilt healthcare component.

The authors propose a possible framework in which the existing public health agencies can actively intervene and collaborate with such community initiatives, to deal more effectively with the health needs of children with intellectual disability. The Medical Colleges and Health Services can function in tandem to provide the machinery for delivery of healthcare services. Wherever possible, the District Mental Health Programme (DMHP) can also be linked to this machinery. National and international research suggests that primary care providers often lack training in the specialised medical, preventive and social service needs of individuals with intellectual disability (Davidson et al, 1995; Martin et al, 1997). Since they are the most frequent providers of healthcare for individuals with intellectual disability (Lennox & Chaplin, 1995), competency in this regard is vital. Training can be provided through the DMHP, by the psychiatrists and their team during their visits to the peripheral institution. To ensure regular checkups for these children, the Department of Health can include 'Buds' schools under the school health programme of the concerned Health Centre. Coordination with DMHP will enable visits by a psychiatrist, at periodic intervals, to deal with those problems which cannot be handled by the Medical Officer of the PHC. Uninterrupted supply of good quality essential drugs, anti-epileptics, drugs for behavioural disorders, first aid kits and other hygiene essentials can be provided through the PHC/ DMHP. Medical Colleges can do the monitoring and evaluation of the healthcare provided in these schools, arrange for specialist care whenever required and serve as the resource centre for technical guidance. Faculty of Medical Colleges can be used to train parents in physiotherapy and speech therapy, in order to ensure sustainable progress where required. It is documented that health providers may have difficulties recognising and treating health problems of such children (Schor et al, 1981; Lennox et al, 1997) and they have very pessimistic views about their roles (Nursery et al, 1990; Siperstein et al, 1994; Lennox et al, 1997). Therefore, all undergraduate and postgraduate students in Medical Colleges need to be trained to handle persons with disabilities of different types, including intellectual disability, and this should also include a change in attitudes.

CONCLUSION AND RECOMMENDATION

Evidence that 'Buds' schools are well utilised suggests that there is a need to propagate this initiative. The system is a boon as it not only nurtures children, but also makes the parents, especially their mothers, more productive and empowered. It is worth replicating this model elsewhere in the world.

However, several healthcare needs of the children are not met. It is necessary to make improvements in infrastructure, human resources and logistics in these schools, because optimising the environment will lead to a favourable health outcome. A comprehensive healthcare programme needs to be developed through the existing system. This is currently not the concern of the Health Department since the schools belong to the local government and only concentrate on the educational needs. A multidisciplinary approach, with the involvement of the Health and Education departments and Local Self Governments, can bring about the desired changes. The aim of providing better quality of life to persons with disabilities, including those with intellectual disability, can be attained only through continuous monitoring and evaluation of the care provided. This study attempts to make such an evaluation. The implementation of the proposed model would facilitate the process of continuous evaluation at periodic intervals, to attain the desired goal.

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