

GLOBAL JOURNAL OF MEDICAL RESEARCH: K INTERDISCIPLINARY Volume 14 Issue 1 Version 1.0 Year 2014 Type: Double Blind Peer Reviewed International Research Journal Publisher: Global Journals Inc. (USA) Online ISSN: 2249-4618 & Print ISSN: 0975-5888

# Differently Abled Children Striving to Lead a Normal Life - What Program Managers Can Do?

## By Saurabh Ram Bihari Lal Shrivastava, Prateek Saurabh Shrivastava & Jegadeesh Ramasamy

Shri Sathya Sai Medical College & Research Institute, India

Abstract- As per World Health Organization estimates more than a billion people live with some form of disability worldwide. Disability casts a significant impact in the development of a disabled child and a constant struggle for the families as well. Multiple political, health care delivery system and social determinants have been identified which have limited the scope of benefit to disabled children. A disabled child represents a vulnerable section of the society because of the socio-psychological restrictions due to disability. The need is to have a comprehensive program for the welfare of the disabled child and their family members to enable them to lead a normal life. To conclude, for doing adequate justice to the differently-abled child, ample scope exists. Political commitment, multi-sectoral involvement and collaboration with international agencies are the main pillars for extending the benefit of welfare measures to the disabled child.

Keywords: disabled, rehabilitation, differently-abled, developing countries.

GJMR-K Classification : NLMC Code: WS 22.1

### DIFFERENT LYABLE DCHIL DRENSTRIVINGTOLEA DANORMALLIFE – WHAT PROGRAMMAN AGER SCANDO'

Strictly as per the compliance and regulations of:



© 2014. Saurabh Ram Bihari Lal Shrivastava, Prateek Saurabh Shrivastava & Jegadeesh Ramasamy. This is a research/review paper, distributed under the terms of the Creative Commons Attribution-Noncommercial 3.0 Unported License http://creativecommons.org/licenses/by-nc/3.0/), permitting all non-commercial use, distribution, and reproduction inany medium, provided the original work is properly cited.

## Differently Abled Children Striving to Lead a Normal Life - What Program Managers Can Do?

Saurabh Ram Bihari Lal Shrivastava<sup>α</sup>, Prateek Saurabh Shrivastava<sup>σ</sup> & Jegadeesh Ramasamy<sup>ρ</sup>

Abstract- As per World Health Organization estimates more than a billion people live with some form of disability worldwide. Disability casts a significant impact in the development of a disabled child and a constant struggle for the families as well. Multiple political, health care delivery system and social determinants have been identified which have limited the scope of benefit to disabled children. A disabled child represents a vulnerable section of the society because of the socio-psychological restrictions due to disability. The need is to have a comprehensive program for the welfare of the disabled child and their family members to enable them to lead a normal life. To conclude, for doing adequate justice to the differently-abled child, ample scope exists. Political commitment, multi-sectoral involvement and collaboration with international agencies are the main pillars for extending the benefit of welfare measures to the disabled child.

*Keywords:* disabled, rehabilitation, differently-abled, developing countries.

#### I. INTRODUCTION

s per World Health Organization estimates more than a billion people (15% of world's population) live with some form of disability. Almost 95 million children in the age group of 0-14 years have some form of disability, of which approximately 13 million suffer from "severe disability" (World Health Organization 2011). An increasing number of disabled infants are surviving into childhood and adulthood, presenting a unique challenge to country's health, education and social care services (Sen & Yurtsever 2007).

#### II. Impact of Disability on Individual, Family & Society

Disability casts a significant impact in the development of a disabled child and a constant struggle for the families as well (Sen & Yurtsever 2007). A disabled child tends to have poorer health related

outcomes - being more vulnerable to preventable conditions like obesity / dental caries / intestinal parasitic infestations (Reinehr et al. 2010 and Nahar et al. 2010 and Tappeh et al. 2010); lower educational opportunities and achievements (World Health Organization 2011); unemployment (World Health Organization 2011); risk of exposure to violence (World Health Organization 2011); numerous types of deprivations - food, housing, access to safe water, sanitation, and health care services (Sen & Yurtsever 2007 and Yousafzai et al. 2011); and increased dependency on others for their development and survival (World Health Organization 2011 and Yousafzai et al. 2011). At the same time, family members have to face multiple challenges such as poor awareness about the child's condition (World Health Organization 2011); adverse impact on social life, working life and family relationships (Sen & Yurtsever 2007); financial constraints (Beecham et al. 2007 and Tolou-Ghamari et al. 2013); and stigma / anxiety / stress / depression (Yousafzai et al. 2011).

#### III. DETERMINANTS FOR POOR HEALTH CARE DELIVERY TO THE DISABLED CHILDREN PROPOSED MEASURES

Multiple political, health care delivery system and social determinants such as inadequate and incomplete policies (viz. lack of financial and other targeted incentives for children with disabilities to attend school or lack of social protection and support services) (World Health Organization 2011); dearth in the provision of health care, support and rehabilitation services (Sen & Yurtsever 2007); shortcomings in the service delivery system (viz. lack of coordination, deficient staffing, and incompetent staff) (Greco et al. 2006); inadequate funding (World Health Organization 2011 and Sen & Yurtsever 2007); negative attitudes / beliefs / prejudices among the stakeholders such as political leaders and employers (World Health Organization 2011 and Sen & Yurtsever 2007); scarce number of institutes for differently-abled thus limiting accessibility (Sen & Yurtsever 2007 and Yousafzai et al. 2011); no involvement of disabled persons in decisionmaking pertaining to matters directly influencing their lives (World Health Organization 2011); and inadequate data & evidence (Read et al. 2010); have been identified which have limited the scope of benefit to disabled children.

Author α: Assistant Professor, Department of Community Medicine, Shri Sathya Sai Medical College & Research Institute, Kancheepuram. e-mail: drshrishri2008@gmail.com

Author o: Assistant Professor, Department of Community Medicine, Shri Sathya Sai Medical College & Research Institute, Kancheepuram. e-mail: prateekbobhate@gmail.com

Author p: Professor & Head, Department of Community Medicine, Shri Sathya Sai Medical College & Research Institute, Kancheepuram. e-mail: jegadeeshramasamy@gmail.com

#### IV. PROPOSED MEASURES

A disabled child represents a vulnerable section of the society because of the socio-psychological restrictions due to disability. The need is to have a comprehensive program for the welfare of the disabled child and their family members to enable them to lead a normal life. Diversified measures should be implemented to exhaustively address the multiple concerns of a disabled child as discussed in Table I. All these measures should be effectively supported with robust childhood disability data collection system and adequate support for encouraging research activities in the field of disabled child.

#### Table I : Potential measures for addressing the concerns of a disabled child

Concerns of a disabled child	Potential measures
Accessibility to health care institutions	<ol> <li>Increasing number of centers offering services to different types of disability</li> <li>Provision of integrated package of services under the same institute</li> <li>Ensuring uniform geographical distribution of the hospitals / centers</li> <li>Advocating structural modifications in facilities to make them user-friendly</li> </ol>
Attitude of health care provider	Involving influential people with disabilities as trainers to improve the attitude and behavior of health care professionals
Creating enabling environment	<ol> <li>Development of specific programs and services for children with disabilities</li> <li>Removing barriers in public accommodations, transport, information, and communication to enable children with disabilities to participate in education, employment, and social life, reducing their isolation and dependency</li> <li>Involvement of non-governmental organizations and international funding agencies for provision of adequate funding support</li> <li>Creation of awareness among the general population using mass media</li> <li>Facilitating early support to disabled children</li> </ol>
Rehabilitation of the disabled child	<ul> <li>Capacity building and human resource development measures:</li> <li>By ensuring training of rehabilitation professionals or community-based workers to address geographical access</li> <li>Fostering community based rehabilitation services</li> <li>Involvement of nursing staff or key workers in the process of rehabilitation</li> </ul>
Education opportunity	<ol> <li>Encouraging inclusion of children with disabilities in mainstream schools</li> <li>Provision of financial support to schools for facilitating such inclusion and bringing about the desired structural renovations</li> <li>Appropriate training of mainstream teachers to deal with disabled children can improve teacher's confidence and skills</li> <li>Advocating establishment of special schools for those disabled children who cannot be integrated in mainstream schools</li> <li>Reservation of seats in professional courses</li> <li>Provision of scholarships</li> </ol>
Employment options	<ol> <li>Vocational rehabilitation</li> <li>Formulation and enforcement of antidiscrimination laws at workplace</li> <li>Application of principles of ergonomics for enhancing their involvement and contribution to the national economy</li> </ol>
Lack of self-belief	<ol> <li>Empowering children to manage their own health through self-management courses</li> <li>Psychological rehabilitation</li> </ol>
Social and financial aspects	A range of financial measures, such as tax incentives or funding for reasonable accommodation, etc
Support to family members	<ol> <li>Trained nurses can be utilized in managing the disabled child in early stages</li> <li>Assisting family in developing good coherence</li> </ol>

#### V. Conclusion

To conclude, for doing adequate justice to the differently abled (previously disabled) child, ample scope exists. Political commitment, multi-sectoral involvement and collaboration with international agencies are the main pillars for extending the benefit of welfare measures to the disabled child.

#### References Références Referencias

 Beecham, J., Sloper, P., Greco, V., & Webb, R., (2007). The costs of key worker support for disabled children and their families. Child Care Health Dev, 33(5), 611-618.

- Greco, V., Sloper, P., Webb, R., & Beecham, J., (2006). Key worker services for disabled children: the views of staff. Health Soc Care Community, 14(6), 445-452.
- Nahar, S. G., Hossain, M. A., Howlader, M. B., & Ahmed, A., (2010). Oral health status of disabled children. Bangladesh Med Res Counc Bull, 36(2), 61-63.

- Read, J., Blackburn, C., & Spencer, N., (2010). Disabled children in the UK: a quality assessment of quantitative data sources. Child Care Health Dev, 36(1), 130-141.
- Reinehr, T., Dobe, M., Winkel, K., Schaefer, A., & Hoffmann, D., (2010). Obesity in disabled children and adolescents: an overlooked group of patients. Dtsch Arztebl Int, 107(15), 268-275.
- Sen, E., & Yurtsever, S., (2007). Difficulties experienced by families with disabled children. J Spec Pediatr Nurs, 12(4), 238-252.
- Tappeh K. H., Mohammadzadeh, H., Rahim, R. N., Barazesh, A., Khashaveh, S., & Taherkhani, H., (2010). Prevalence of intestinal parasitic infections among mentally disabled children and adults of Urmia, Iran. Iran J Parasitol, 5(2), 60-64.
- Tolou-Ghamari Z., Shaygannejad, V., & Khorvash, F., (2013). Preliminary investigation of economics issues in hospitalized patients with stroke. Int J Prev Med, 4(Suppl 2), S338-342.
- Yousafzai, A. K., Farrukh, Z., & Khan, K., (2011). A source of strength and empowerment? An exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. Disabil Rehabil, 33(12), 989-998.
- 10. World Health Organization. (2011). World report on disability. WHO Press: Geneva.