



Concept Paper:

It's Time to Make Inclusivity and Positive Rehabilitation The Basic Right of Children With Down Syndrome: A Pakistani Perspective

Saadia Shahzad

Department of Community Medicine, Shalamar Medical and Dental College, Lahore.

ABSTRACT

Social inclusion and positive rehabilitation of children with Down syndrome (DS) is the need of the hour in our society; which can be achieved by following the right principles and strategies. The current status regarding this issue at the local level has been analyzed and compared with the global status, and gaps have been identified. The author of this paper has put forward the argument that *inclusivity of persons with DS ought to be the norm of this society, and early intervention onset and support mechanism of a comprehensive nature can develop these children into self-supporting independent persons*. Priorities and a way forward are suggested through a very comprehensive model for the local setup in Pakistan.

Keywords: Down syndrome, social inclusion, local situation, global situation, gaps, model

INTRODUCTION

In the developed world progressive research and development in rehabilitation and social inclusion of children with Down syndrome (DS) has played a phenomenal role in the upbringing of these children to the level of becoming independent and productive members of society. Whereas the situation is almost in contrast in developing countries and especially in Pakistan. Three decades back the term DS never warranted any attention from the special education and rehabilitation personnel; hence no formal/informal rehabilitation program for them. Then there was some change in the scene and special needs schools started mushrooming in abundance in our local setup; still with no actual awareness of how to rehabilitate DS children to their optimum capacity, thus making them constructive members of the society. For the past, twenty years enhanced awareness regarding DS started infiltrating the minds of society to some extent and efforts were put in practically to incorporate these children into the special education system, to give them skill training, but rarely in an integrated educational plan. And this started happening when parents themselves came to the front with positive rehab of their child and making him/ her a success story. But these individual efforts required herculean efforts by the parents to get their child to this level.

This concept paper is an effort to accumulate the experiential facts on the ground, compare them with the global situation, and come up with a first-of-its-

kind working model for the positive rehabilitation and social inclusion of DS children to the utmost; benefit all the stakeholders i.e. DS child/ person, parents/ immediate family, and society at large.

CONCEPT PAPER

Preamble:

The UN Sustainable Development Goals (SDGs) were based upon one principle that stated "equitable and universal access to quality education at all levels, health care and social protection; where physical, mental, and social wellbeing are assured"¹. In a nutshell, this vision of a healthy society included differently abled and challenged children too. The UN Convention on the Rights of the Child (CRC) further imposed that no child with any disability must be left out from mandatory primary and secondary education on account of their physical or mental challenge². Successful inclusion in schools and society can follow the principles given by Salend³. These principles are:

- **First:** Learner shares equal access, defining it as placing all the learners together in general education classrooms regardless of their learning ability, economic status, gender, learning style, ethnicity, religion, cultural background, family structure, and sexual orientation³.
- **Second:** Focusing on individual strengths, needs, and diversity. Where diversity is defined as an inclusive classroom where all students are valued as individuals capable of learning and contributing to society. They are taught to appreciate diversity, to

value and learn from each other's similarities and differences³.

- **Third:** Effective inclusion requires adopting reflective practices by the educators and practicing differentiation in their assessment techniques, differentiation in teaching methods, and classroom management. Teachers must see each child with their specific needs and strengths³.

- **Fourth:** Successful inclusion needs collaboration from all stakeholders: educators, parents, families, society, Government, and agencies³.

Teachers feel apprehensive by the presence of a special needs child in their regular class as if it is a test of their capabilities⁴. Although developed countries like USA and UK are leading in adopting and effectively implementing a positive approach towards the inclusion of such children in the mainstream education system⁵ in Pakistan collaboration between special education and mainstream education department is grossly lacking; gravely impacting the societal view of the special gifted children. The last principle by Salend³ shows that the involvement of all the stakeholders is the key driver in this chain for the successful rehabilitation of special needs children in a community. Parents/ families/ society's attitude is critical and plays an important role in the process of getting the child included in a mainstream regular school⁶.

The past four decades of exploratory and applied research in developed countries in the sphere of positive rehabilitation and social inclusion of children with Down syndrome (DS), had achieved fruitful results. Globally it is estimated that 70% of children with disability including intellectual challenges of mild to moderate degree, are capable of attending regular schools; provided the institution has a supportive, encouraging/ conducive, and customized environment for these students; showing that they are willing to accommodate the children⁷. UNICEF strongly urges that the ultimate goal should be to enable all such children to become independent and productive members of society and take part in the development of their community. To meet this daunting goal, all structures and stakeholders need to collaborate and provide community-based contemporary services; accessible to all without discrimination⁷.

Current Status Regarding the Issue:

Local level:

History reveals that in Pakistan teaching and training of special needs children/ adults was in the domain of religious bodies, which were in a minimal number at the time of independence. After

independence, a few private organizations also came into the field for this purpose⁷. In 1959 The National Commission on Education for the first time placed the agenda of provision of vocational education for children/ adults with mental challenges, as well as training of teachers for this specific purpose⁷. The education policy of 1972 allocated funds for special education, for the first time⁷. In the decades of 80s and 90s, The UN asked its member states to focus on the challenges/ problems of special needs persons (though there was no categorization of different disabilities as such); after publishing their report in this regard⁷. Hence Government of Pakistan at that time increased its allocated budget to many special education institutions, and as a result, more than 200 institutions came into being. As per personal experience, I feel that the findings of this report and its recommendations are very much valid for the vulnerable population in question; and more importantly, these are still unmet in our setup since 2003. In Pakistan, the scope of this problem includes:

1. **Scant research on Down syndrome (DS) and their rehabilitation:** Regarding perceptions of parents and immediate family, problems faced by parents and families, perceptions of teachers in mainstream schools, the approach of teachers towards DS children and their rehabilitation, perceptions of the community regarding this concept and fact, scope and impact of awareness campaigns in this regard.

2. **Social perception and social fabric:** One of the biggest hindrances to progress in this area is the social perception and social fabric of our country. Till the last decade least interest and value were given to a child with a disability at the family, as well as societal level.

3. **Understanding of the DS child status:** There is a gross lack of understanding of the proven fact that children with mild to moderate deficiency (IQ of 40-70) will benefit more with constructive social inclusion at all levels; enhancing their capabilities.

4. **Lack of social awareness:** Additionally, the problem is overshadowed by the lack of awareness in society at large and the socio-economic status of a developing country.

5. **Lack of contemporary professional expertise:** Capacity building of the professional staff is required at all levels for inclusive rehabilitation.

All these factors contribute towards the minimal creation of opportunities for children with DS.

Against this background, this paper argues that: since the ethical principle of respect for the person

and the best interest of the child (and no harm/ less harm to the child) are imperatives, inclusivity of persons with DS in society ought to be the norm. For this social inclusivity to happen it is important to know (and overcome) the hindrances. Inclusion in educational institutions and thus social inclusion of DS persons depends on some factors that can be separated into the following domains:

1. Family: Parental literacy, socio-economic status, family size (number of children in the family), philosophy of life in a household, attitudes of parents and family members, and family influence in a society like ours.

Above all the will and determination of parents as groups is the key driver behind the achievement of this change in a community. Though many parents are working at the individual level in our country coordination and collaboration among all of them is missing; as a result, unified influence is not achieved at the required levels in the society. Parents' attitude in all respect within the home and outside is the foundation stone for making a positive outcome-based road map of rehabilitation. Research has shown that the key points driving towards choosing or not choosing inclusive education might depend upon basic socio-demographic factors.

2. Societal:

a) Social attitudes: Cultural and social norms, and lack of correct societal awareness towards this concept and its desired outcome.

b) Social awareness: At the policy level, expert human resource for inclusive education, intervention services' availability, and accessibility by all (from the very start), education experts who are well aware of the idea of inclusiveness of DS children, planning and implementation of the right policies for these children at the state level (since there are none at the moment), and inter-sectoral collaboration.

Furthermore, the ethical concept of the best interest of the child and no harm/ less harm to the child is applicable in this situation. It needs to be practiced both by the parents/ family and the society at large⁸. Research has shown that the key points driving towards choosing or not choosing inclusive education might depend upon basic socio-demographic factors⁹.

Inclusive education in Pakistan was started in 1994 by the forceful push of UNICEF; which started the system of enrolling children with disabilities in every school¹⁰. It was reported in a previous study that mainstream schools are a much better opportunity for children with disabilities; if the problems associated with teaching these children in mainstream schools are tackled appropriately by

expert staff¹¹. In a study conducted by UNICEF, the focus was on the policies and practices in inclusive education for children with disabilities in Pakistan⁷. The few inclusive schools that demonstrate good practices are limited to bigger cities and in the private sector; neither accessible nor affordable to all⁷. There is a lack of knowledge as to what capability the differently abled children can have superimposed by the lack of educational facilities, this puts them in a very low profile.⁷ At the local level for DS children there is a gross lack of awareness for rehabilitation; inclusive education; comprehensive social inclusion; support, counseling/ mentor system for parents; coordination between the Ministry of Education, Social Welfare, and Special Education; and early intervention system. Even at the Federal level in Pakistan, the implications for inclusive education for DS children are recognized in principle only and not practiced at a larger scale⁷. *My argument is: that early intervention onset and support mechanisms of a comprehensive nature can develop these children into self-supporting independent persons.*

Making a child with DS an independent member of society is the desired outcome when all the rehabilitation programs are working. Thus DS persons are having a much fuller life in the West as compared to developing countries. Locally, to date, the following has been done.

1. There is an increased number of special needs schools in both the public and private sectors that take in some number of DS children as per their vacancies.
2. Special Olympics Pakistan is giving opportunities to children with DS in sports.
3. Mainstream inclusive education is available in a scant number of schools, but the whole package is unaffordable for the majority. Furthermore, teachers in mainstream schools are not specifically trained for this purpose.
4. Some parent support groups have evolved in the past decade that are trying to give support to parents; again in bigger cities and among affluent populations. A few groups of affected and educated parents joined hands to make organizations like Karachi Down Syndrome Program (KDSP) for rehabilitation purposes, providing good services to the community.
5. Few organizations in the private sector are providing structured programs for job placement for children with disability (physical); but not for DS children on account of their mental challenges.
6. McDonald's (an International franchise) is offering a structured job placement program for

well-rehabilitated DS children/ persons too, for the past ten years or so.

Global level

Globally in the past 5-6 decades, vast exploratory and applied research has been conducted in the area of DS. Studies have been conducted to search the impact of having a child with DS on family¹², support system¹³, community values¹⁴, structured rehabilitation program, independent development, job customization and placement, and many other areas of life. West has identified as many as twenty research gaps still, in the area of rehabilitation of DS and its impact; to name a few better characterization of the natural history of cognition, language, and behavior, identification of mental health comorbidities, and risk and protective factors for their development, understanding the effects of educational and social services and supports. Globally current state of knowledge regarding DS encompasses the areas of epidemiology, physical and mental health, cognitive and linguistic profiles, aging, impact on family, and current strategies for educating professionals, families, and the general population at large; has been studied¹⁵.

Local	Global
Scant research in DS rehab; Unable to make use of the global research evidence in this regard	Optimum applied research in the area of DS rehabilitation.
Minimal awareness in the majority local population regarding DS rehabilitation and inclusion	Social awareness of DS inclusion across cultures is better ¹⁶ .
Early intervention programs grossly missing for the child after birth	Early intervention is available from day one of birth and its effectiveness is determined ¹⁷ .
No formal support services are available to parents and families (counseling, guidance, social support, a mentor system, etc)	Early intervention is available for mothers ⁶ .
No affordable structured occupational therapy services available to all	Contemporary methods are available to all.
Capacity building of specialized human resources for DS inclusion and rehabilitation is missing	A large number of DS rehabilitation experts are available.
Registration as a citizen with the issuance of SCNIC through disability certificate issuance; has started recently ¹⁹ . <i>The implementation of the benefits (health coverage, transport/ fare coverage, etc) of this is yet to be seen for DS children/ persons</i>	All basic facilities and services are covered for DS children
A formal policy for social inclusion at the school level/ customized skill training/ job placement/ entrepreneurship/ social	UNICEF's newer revised guidelines clearly state the inclusion ²¹ .

clubs' services is in place, <i>but its effective implementation is not there at all for DS persons</i> ²⁰ .	
Child Protection Bill does not state the term Down syndrome specifically ²² . <i>So things are left to the perception of the reader.</i>	The National Down Syndrome Society (USA) Advocacy & Public Policy team works directly with legislators and administrators to make sure their work is increasingly inclusive of the Down syndrome community and progressively beneficial.
No authentic and specialized central record maintenance of DS person	Record maintenance is there
Lack of collaboration between the stakeholders (mainstream education, special education, legal, social/ welfare services, health care, and families); for inclusive rehabilitation of DS children	UNICEF's newer revised guidelines clearly state the significance of collaboration between the stakeholders ²¹ .
Lack of collaboration between current resources working for DS children; in both the public and private sector	Collaboration is there as many such organizations are working across the globe e.g. NDSS in the USA, Down syndrome association UK, DS Association Scotland.

Table-1: Gaps in the handling of this problem locally and comparative Global situation.

Few parents and special institutions understand the philosophy behind the rehabilitation of DS children duly supported with scientific evidence. As a result, there is a gross difference in the results for DS children in Pakistan and globally.

Priorities and Suggested Way Forward in Pakistan:

As a Public Health Specialist, I propose the following model for the rehabilitation of children with DS. It is important to understand that DS children/ persons have different needs as compared to other physical as well as mental disabilities; and the Disability Act, 2020 by the Government of Pakistan does not take into account this significant difference. As a result, things have not worked out well for children with DS upto now. I have tried to take into account all the required organizations and levels of society for the successful rehabilitation of DS children; with the outcome of making them productive members of society and independent and confident individuals. Still, in my opinion, this model will not be practically successful unless and

until maximal sensitization upon it is done for all stakeholders and State/ society to join hands in it.

As the result of my experiential learning, and as a Public Health specialist I have tried to develop a working model for this purpose. I propose the following working model for the rehabilitation and social inclusion of children with DS:

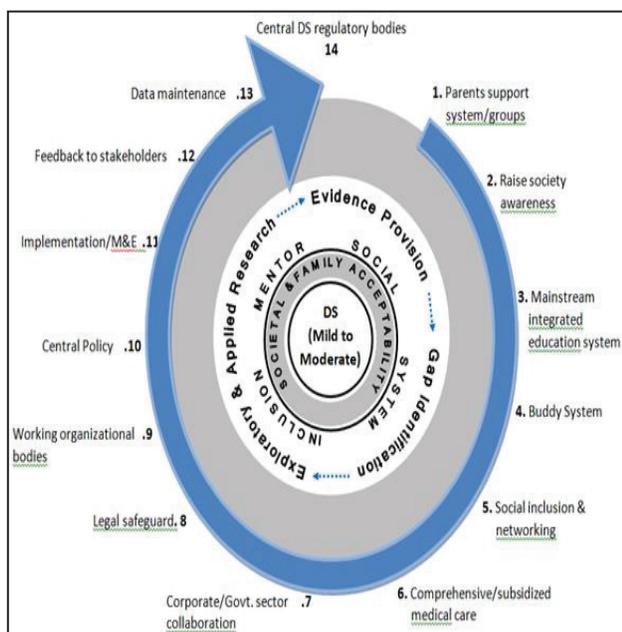


Fig-1: Model for the positive rehabilitation of children with Down syndrome.

1. Parent support groups should be developed to build networking among the parents and support system development.
2. Society awareness needs to be raised through various sustained long-term strategies like the use of electronic/ print media, seminars, talks, and symposia; on a war footing.
3. The mainstream integrated educational system can be effectively pulled up through capacity building of the staff for this specific purpose; Individual Educational Plan development; and pulled-back programs.
4. A reliable and trustworthy peer and buddy system needs to be introduced in society at all levels for these children, starting from the household level. These children have a great tendency and capability of learning by imitating others and the buddy system encourages them to a great extent.
5. Social inclusion and networking can be achieved through membership in social clubs/ sports clubs/ public events and household events etc.

6. Subsidized medical care is a need that can only be provided through central policy implementation.
7. Collaboration of government and private sector is necessary for the creation of customized skill training opportunities; customized job creation where needed and sustenance of these activities.
8. Legal safeguard of DS children through the right policy making, implementation, and monitoring and evaluation (M & E).
9. Working organizational bodies are a combination of policy makers + learned parents who have personal experience with DS child rehabilitation.
10. Central policy-making specifically for DS children/ persons is needed as all types of disabilities have a different scope of rehabilitation
11. Implementation and then M & E of the policies is very important to meet the objectives.
12. Feedback should be disseminated to the stakeholders at individual and collective levels
13. There is a dire need for authentic record maintenance of DS children and persons with details of the level of challenge.
14. Central DS regulatory bodies are required at the provincial as well as central levels, to manage the system of rehabilitation for the DS children/ persons.

CONCLUSION

Educated and experienced parents who have worked with their such children need to get together in greater numbers to build up their resources that work for the improvement of this situation in the suggested model, supported by philanthropists, special education experts, educationists, health care professionals and things can be set in motion at some pace. There is a dire need for policy making upon social inclusion for DS children that takes into account all the required levels of positive rehabilitation, with the clear and precise outcome of making these children confident, positive, and productive human beings. They must not become a liability for themselves, family, and society; when they have all the capability of becoming constructive members in all respects. Stakeholders need to work hand in hand, and drivers would definitely be these parents themselves, there is no other option or solution to it locally.

I as a mother of a son with DS and a Public Health Specialist, reinforce the arguments given above with my practical life example and stand by my arguments that acceptance, inclusiveness, social

support, the Best interest of the child, no harm/ less harm to the child, result in oriented efforts to achieve the objectives; all are contributive towards the development of a DS child into an independent and productive member of the family and society. My son is working in the McDonald's chain on half time salaried job since 2017 and recently got promoted to Training Manager in Sep 2021. I support my argument given above that parents need to become unified and start helping each other and society to understand the problem and work in a result-oriented manner. The practical example is there to support it too as I am the founder of a parent support group myself and another has been mentioned above.

I can vouch with all my conviction that these children are better human beings than many of us on account of their innocent character, love, friendliness, caring attitude, and untiring willingness to learn with due encouragement and guidance. We need to learn from them the art of being better human beings. They bring with them sunshine of happiness and love and smiles.

STATEMENTS OF DECLARATION

Funding: the author declares that no fund, grant, or other support was received during the preparation of this manuscript.

Competing interests: the author has no relevant financial or non-financial interests to disclose. This article was presented by the author at the **14th World Conference on Bioethics, Medical Ethics, and Health Law in Porto, Portugal in March 2022.**

Author contribution: I am the sole author of this manuscript conception, working model design, and write-up.

Ethics approval: ethics approval was not required as this was a thought paper and no human subject was involved in any data collection, so consent to participate was not required.

Consent for publication: the author consents to the publication of the manuscript with the condition that the model developed and given in the manuscript shall not be published separately by another name and the copyrights of the given model will stay with the author.

STRENGTHS

Locally scant research work has been done in this specific area. Hence, this concept paper will be a comprehensive addition of experiential knowledge and ground realities combined. It can be taken as the

foundation and varied avenues for future research can open from it. For the reader's interest and benefit of the researchers, the author has built up the concept as a story; building from the historical past to newer situations.

LIMITATIONS

The major limitation of this article is that the author had to use older references as historical background and guidelines for this issue had to be given. Moreover, newer references from the local setup also could not be found due to the paucity of research in this area.

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Corresponding Author:

Dr.Saadia Shahzad,
Associate Professor,
Community Medicine,
Shalamar Medical and Dental College, Lahore.
Email: saadiazahur@live.com