Early Intervention in Developmental Disabilities

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Abstract: The developmental period of a child has critical importance for learning and it is even more so in case of a disabled child. The earlier the disability is detected, the easier it is to effectively help the child both medically and educationally. The present paper is an attempt to define and describe developmental disability both as a concept and as a practical program of intervention. The main emphasis was on educational intervention in order to help the disabled children with learning in their developmental period.

Key words: Intervention · Developmental Disability · Interdisciplinary · Cognitively oriented

INTRODUCTION

The topic to be discussed presently has three terminological components. Technical terms contribute to confusion and it is always helpful to clarify, at the first opportunity, the precise meanings of the terms used in a discourse. Let us take the terms employed in the present topic in reverse order and make an attempt an understanding them.

All present should have an idea, at least a rough idea, of the meaning of the first term “Developmental Disability” a combination of two words, development and disability. Since all the topics to be discussed focus around this term it is even more important to clearly, grasp its import. The term was first coined in the sixties to cater to a legislative requirement in the U.S concerning governmental provisions for disabled children. Initially the term was defined as:

“All of the life long disabling conditions that require similar treatment or helping services and that occurred prior to age 22” [1]. The term was not to include disabilities that effectively could be overcome with rehabilitation or that were not both apparent and disabling prior to age 18. Since the original definition was closely related to the field of mental retardation and appeared somewhat restrictive in its application it was later on changed and made more flexible. Today, the term developmental disabilities are used as redefined in developmental disabilities. Act of 1984 (PL 98-527) which states: According to the term Development Disability means a severe chronic disability of a person which:

- Is attributable to a mental or physical impairment.
- Is manifested before the person attains age 22.
- Is likely to continue indefinitely.
- Results in substantial functional limitations in three or more of the following areas of major life activities:
  - Self care (2) Receptive and expressive language (3) Learning (4) Mobility (5) Self direction (6) Capacity for independent living and (7) Economic sufficiency and reflects the person’s need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of life long or extended duration and are individually planned and coordinated. [2]

It appears that in years to come the term may be further mellowed and made more flexible as to include all types of disabilities which can act as hindrance to development. N the same spirit, it is likely that its curative and ameliorative scope will also widen making the development possibilities for disabled children more effective and meaningful.

The second term “intervention” also carries special meanings which are somewhat at odds with the general use of this word. In daily parlance the word intervention carries a connotation of uncalled for interruption of an ongoing activity. Its recent use in the field of education, particularly, in special education still means, an interruption but a warranted and deliberate interruption with a specific objective. The term significances a medicated attempt to check and counter the disability in a way so as not to allow it to develop into a handicap. In this context Bailey and Smith [3] attached great importance and state:

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“In a narrow sense” early intervention means to carry out a therapeutic and educational program in order to guarantee the development of infants and children with disabilities who have a high risk of having their development disrupted by medical and environmental factors. It also refers to such a systematic program itself. Examples of high-risk infants are immature infants whose development is disrupted by medical factors and infants who are raised in extremely unfavorable environments.

More broadly, “early intervention” means to build a social network so as to help such children’s parent and family directly or indirectly, in addition to administering to the infants the therapeutic program described above. Even if some infants having problems are detected in the early stages of development, the children’s development cannot be guaranteed unless the earliest possible intervention is offered. From the point of view of mainstreaming, which secrete the right of children with disabilities to live in the same environment as children without disabilities, a local therapeutic system necessary for the development of a social network?

The meaning of word “early” is the same as used in daily intercourse in the particular context of development disability; however, the word signifies the maximally possible earliest prevention, detection and intervention of disability among children.

The combined meanings of these three terms point out to a filed of disability which is receiving increasing attention among those concerned with special education programs all over the globe. Naturally the developed countries have taken leas and have made important advancement in early intervention strategies and provisions. In contrast, the developing countries are either far behind of just beginning to take interest in this area. What has given impetus to the need of early intervention is the increasing realization that in the developmental process early years represent the most important and formative period.

Since the 1960’s there have been literally hundreds of studies attempting to determine the effects of early intervention on disadvantages and handicapped children. In a review of reviews, Spiker, Hebbeler, Wagner, and McKenna [4] found that 94% of a sample of 52 previous reviewers of the early intervention literature concluded that early intervention resulted in substantial immediate benefits for handicapped, at-risk and disadvantaged children. The immediate benefits included improved cognitive, language social-emotional and motor growth and better relationships and functioning with parents and siblings. In an analysis of the long term effects of early intervention, Lazar and Darlington [5] pooled the data from 12 follow-up studies of children who had participated in cognitively oriented preschool programs for socio-economically disadvantaged children. At the time of the follow-up studies, the children who had participated in the pre-school programs were in the 3rd to the 12th grades. Fewer of the early intervention children had been placed in special education classes (14% v. 29%) and fewer had been held back to repeat a school year (26% vs. 37%) [6] In the first place, the experience gained by children at this time lay down the blueprint of human personalities and secondly, the hindrances or obstacles to growth can also be more easily and effectively checked and controlled in their inception. In case of disabled children early period of life is even more crucial both with respect to the special nature of their developmental needs and the possibly longer duration of early life. [7]

States the following three ethical arguments for early intervention,

Preventing the child from learning incompetence by promoting greater independence.

Removing the continued burden to society by reducing the child’s long-term needs for intensive and expensive resources and

Changing the public’s attitudes toward the handicapped individuals by demonstrating the benefits of early intervention programs in decreasing handicapped people’s dependence on public support.

In special children disability generates special needs and its onset in them not in-frequently starts before birth. For the purpose of prevention of disability it is essential to pay attention to abnormalities and complications of conception and the growth of child prior to birth. Effective intervention can only be based on a three tier program, namely prevention, detection and actual intervention. Preventive strategies by their very logic seek to encompass the earliest possible period of a child’s life. Certain congenital diseases and abnormalities which are caused either by consanguous marital practices or other genetic aberrations can be effectively checked if parents can have access to prior knowledge about the. Similarly, precautions during pregnancy and safety provisions in early childhood can prevent the incidence of disability. Nutritional deficiencies leading to disability can also be overcome more easily and effectively in the early stage of life.

Haring in his book [8] gives a table to present family function to show the wide areas which are widely affected by the positive cooperation between children and their parents.
### Table: Family functions

<table>
<thead>
<tr>
<th>Economic</th>
<th>Physical</th>
<th>Rest and Recuperation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generating income</td>
<td>Food purchase and preparation</td>
<td>Individual and family-oriented recreation</td>
</tr>
<tr>
<td>Paying bills and banking</td>
<td>Clothes purchase and alteration</td>
<td>Release from demands</td>
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<tr>
<td>Handling investments</td>
<td>Health care and maintenance</td>
<td>Development and enjoyment of hobbies</td>
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<tr>
<td>Overseeing insurance and benefit programs</td>
<td>Safety and protection</td>
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<tr>
<td>Earning allowance</td>
<td>Transportation</td>
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<tr>
<td>Dispensing allowance</td>
<td>Home maintenance</td>
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<tr>
<td>Socialization</td>
<td>Self-definition</td>
<td>Affection</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>Establishing self-identity and self-image</td>
<td>Nurturing and love</td>
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<tr>
<td>Social skills</td>
<td>Recognizing strengths and weaknesses</td>
<td>Companionship</td>
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<td></td>
<td>Providing a senses of belonging</td>
<td>Intimacy</td>
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<tr>
<td>Guidance</td>
<td>Education</td>
<td>Emotional expression</td>
</tr>
<tr>
<td>Problem solving</td>
<td>Continuing education for parents</td>
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<tr>
<td>Advising and giving feedback</td>
<td>School work</td>
<td>Career choice</td>
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<tr>
<td>Shaping basic beliefs and values</td>
<td>Homework</td>
<td>Development of work ethic</td>
</tr>
<tr>
<td>Transmitting religious values</td>
<td>Cultural appreciation</td>
<td>Support of career interests</td>
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**Families Perform many Functions:** As many as nine family functions have been identified in the literature (Benson and Turnbull, in Press): economic, physical, rest and recuperation, socialization, self-definition, affection, guidance, education and vocational. These nine functions and the specific tasks associated with each are listed in Table.

In case of detection also the sooner the disabilities are detected the better. It will not be wrong to assume that in early life disability is more malleable and amenable to care and can be checked more easily through medical programs. Early detection is also important from a developmental perspective when secondary effects of a disability are taken into view. Secondary effects are those as are added to an already difficult situation through interaction of disability with environmental factors. For instance, it is difficult for parents to reconcile with, much less to comprehend the causes of disability of their offspring. Their negative attitude, in general and the loss of time in graining and understanding of the problems to an extent where parents would be willing to sock professional help complicates the disability situation to its confounding limits. Similarly the general treatment received at the hands of peers and others, if left unchecked for a length of time, hardens the disability and creates general attitudinal problems and complexes among disabled children. In formulating intervention programmed whether medical, social or educational, early detection is always helpful and contributes to the development of effective strategies.

Intervention, which represents the third and the most important of their ameliorative strategies, is a logical consequence of detections. It carries the meanings of actually coming to grips with the problem and to deal with disability in all its dimensions. This should signify that dealing with disability is not a simple but complex problem which leads us in to numerous professional fields. The experts needed to help the problem hail from diverse fields and include psychologists, social workers, doctors, therapists, teachers and paramedics. Once expertise in different fields is available it is also necessary to organize it in a network of coordinated services which can be made available to special children.

The second and even more important aspect of early intervention relates to the active involvement of parents and the community. Mary [9] has shown the current trends in Intervention which are totally based on involvement of family. “The focus of services has shifted from child-centered to family-centered and family directed intervention. Families are acknowledged as unique and able to identify their own concerns, priorities and resources. The term family-centered in this context refers to particular ways of working with families as described by McWilliam [10]. The beliefs and practices of family-centered services are consumer-driven and competency-enhancing. Families participate as decision-makers and partners in planning and implementing the service delivery process. Intervention goals focus on strengthening and supporting the family system as it adjusts to the needs of a member with special needs.

The family-centered focus has had a significant impact on early intervention methods, parents or caregivers and other family member now enter into partnership with professionals in all aspects of early
intervention conducting assessment, prioritizing intervention goals, designing intervention plans and implementing intervention”. The period of early life and its development is the direct concern of parents and ameliorative service should be made available to them at the level of the community in which the child resides. This calls for strategies which can inform, educate and train parents and also induce the community members to develop various services, principally based on local resources------less an infrastructure is developed at the community level, intervention cannot be expected to be effective and meaningful.

In developing a practical and effective system of prevention, detection and intervention, considerations of a general natural will also have to be taken into account. Two of these deserve mention. The first is the need for development of trained personnel and staff to carry out different service tasks. Present specialist training in medicine, education, psychology and social work is not adapted to actual working with the young disabled children and often lack, adequate knowledge of the problems of early detection and intervention. Further, professional training programmes presently available, do not prepare students for the type of multi-disciplinary team work needed in early care service.

The other need is that of generation and dissemination of information. The quantity and quality of services for handicapped children normally depend upon the general level of knowledge in a society. In countries where literacy is poor and old belief and superstitions prevail, there is bound to be low, motivation to develop services. Without a sound information base, it is not possible for parents to help their handicapped children. Thus in early care services the dissemination and promotion of knowledge is imperative in formulating a policy aimed at developing early care services.

Based on these broad hints for setting up a system of early intervention, every country, whether developed or developing, will have to chalk out its own unique course of action. Any attempt to develop a uniform system for all societies is bound to run frustration and is likely to prove counter productive. The developed countries are wide apart from the developing countries both in terms of quantity and quality of child care services. Even the concept of disability as perceived by the two sets of countries is not identical. The developed countries have reached a level where they can see disability in all its finest implications and take care of it in the best possible manner. This is not the case in developing countries where there is chronic stringency of resources.

The following is a summary of Nancy’s views on the cost of maintaining one handicapped person in a state institution. This may exceed $40,000 per year. With in the community the handicapped often require special housing, transportation, health services, sheltered employment of work training, food and clothing and other support. When so much money is spent on expensive services for a small percentage of the population a society under economic stress often looks for a scapegoat the evidence bears out limited success of intervention with late school-aged and adult handicapped person. The ethical arguments for early intervention then encompass three issues:

- Preventing the child from learning incompetence by promoting greater independence
- Removing the continued burden to society by reducing the child’s long term needs.
- Changing the benefits of early intervention programmes.

The available facilities in terms of experts and information are only conspicuous by their absence. This means that the initial effort to set up a system of early intervention can not be any thing but modest. Even developing countries among them cannot afford a uniform pattern. Each country has its own exigencies, cultural conditions and particular ways of doing things which differentiate it from the other. This is not to say that developing countries cannot learn form global practices or from the experiments conducted in other developing countries. There is much in common in the status of the problem and in the experiences encountered in the field and practices adopted in one country with necessary modification can be made use of in a different country. The important point to understand is that an alien system in its totality cannot be transplanted form one country to another. Even isolated practices if borrowed from another country will have to be modified and prepared to fit into the new situation.

With these reservations references can be made to a UNESCO Project which was conducted in 1978-79 and included selected case studies of nine countries, both developed and developing, surveying the status of progress concerning early intervention. The case studies present nine different models. Each represents its own situation and conditions. The purpose of the UNESCO study was to describe the situation of early care of handicapped children in a way that could be useful for the future development of policies and services in different
countries. This study also brought out certain suggestions which reflect trends experienced commonly by different countries. Mitchell [11] has given the following recommendations for practical work with reference third world countries which are taking the first step in these directions.

- Early intervention in TWC’s should be focused on the prevention or amelioration of disability.
- Screening for this purpose should concentrate on conditions feasible with available resources.
- Procedures used for screening should:
  - Provide a profile of the individual’s strengths and weaknesses across several domains.
  - Provide some preliminary guidance on how intervention should proceed.
  - Ideally the guidance for intervention provided by professional assessment should specify criteria for evaluating its impact.
- Early intervention should give priority to ensuring that the child’s regular effective environment provides individualized attention and consistent emotional support. The most effective way of doing so in most TWC’s will normally involved strengthening the family into which the child is born, or in exceptional cases, placement of the child in a small foster home.
- Home-based programs should aim to build on the moral and emotional commitment of the family towards the child’s welfare.
- Several levels of personnel are required for the effective implementation of community and home-based programs of early interventions and suitable training should be organized each level.
- New techniques which are considered locally applicable sold be made available with appropriate training to as wide a spectrum of potential agents as possible, including parents, other family members, front in-line personnel of generic education, health and social services and traditional health practitioners.
- Client families and communities should be fully involved in the setting of targets for services and in the monitoring and evaluation of their attainment.

In the first instance, there is increasing realization among countries that early detection responsibility. This means that early care does not mean merely institutional care or that is can be entrusted to a few specialists. Cooperation within family, school and community as well as the need for creating awareness for handicap problems is essential. By the same logic and interacting team is the most suitable work model for early intervention services. According to Hallaban [12] “Individuals and ideas have play crucial roles in history of special education, but it is accurate to say that much of the progress made over the years has been achieved primarily by the collective efforts of professionals and parents.”

The second issue highlights family as the basic unit for care. For the handicapped child family is the most valuable assets. The child is part of a social network and his most frequent and intense interaction is with family members. For disabled child the parent’s knowledge of handicapping conditions s a key factor and thus there is a strong need for the dissemination of knowledge about handicap problems to parents. Effective work model for early child care can only be developed around parental care and involvement.

A third issue emphasis diversity of child care services working with a high degree of coordination. Services for handicapped children are offered by various agencies, central government, provincial and local councils and voluntary organizations. Different professionals are also involved and to list a few, include physicians, nurses, psychologist; teachers and speech therapists. There is a definite need that all those involved in setting up early care services should be part of a network and work in cooperation and unison.

Education policy for the Education and Rehabilitations of the disabled [13]. Also has given emphasis on this aspect.

- There is need to coordinate the efforts of a large number of agencies each of which has a distinctive contribution to make. The need to evolve coordinated approach to the training of medical practitioner, paramedical workers, social workers, teachers and other professionals argues strongly for a National Standing Committee on Professional Training and Research in Special Education and Rehabilitation.
- The training of doctors in the diagnosis of disability, developmental pediatrics and other related specialisms will provide a necessary underpinning for the future growth of services for the disabled in Pakistan. A review of current basic training should be undertaken by the relevant authorities as a matter of urgency and courses of advanced study in particular specialisms provided, within the shortest possible time.
The number of training places available for occupational therapy and physiotherapy should be doubled and a training course for speech therapists be established in a university centre by the end of 1989.

Another important issue concerns the trend towards integration and normalization. Integration has given a specific direction to reforms in the filed of handicapped care and special education. It is regard both as a goal for services and a characteristic feature of the services. It is a goal to help the child develop such skills and such self concepts as are necessary for satisfactory participation in social life and work. The way to achieve this is to let the handicapped child grow up in close context with other children as opposed to referring him to an isolated or segregated environment.

These broad suggestions, which reflect a consensus of opinion, both among developed and developing countries can be used as a guideline by developing countries that are at the initial stages in developing an early intervention system to cater to the needs of handicapped children.

Pakistan, as in other social service sectors, is a late starter in the filed of special education also. In fact, government effort in the field received an impetus and became meaningful only at the end of seventies. It is heartening to note that in formulating a policy for special education there has always been a realization that early intervention must receive a pivotal importance in planning long-term provisions. Even in the early policy documents, outlining developmental plans for disabled children, we come across passages such as:

National and international experience gained in this field indicates that it is possible to prevent physical impairment form becoming a disability and a simple disability from becoming a life-long handicap with adequate and timely care, treatment and training of the disabled child and proper guidance and help of its parents. Most of the needs of the preschools child can be met by the parents themselves and or with the guidance, counseling and support of the community based health and rehabilitative services. There is a special need for health services in the pre-school period of the child. Early detection, correct diagnosis, adequate timely treatments of the disabled child is essential since it can cure its physical impairment in many cases and arrest its deterioration in many others from becoming a disability.

In later government publication also attention has been drawn to the formulation and adoption of early intervention strategies. These good intentions, however, bog down when we encounter actual implementation and setting up of concrete facilities and provisions for the purpose. It seems that the sustained energy which practical schemes of a longer duration require, is lacking and projects launched with a brimming enthusiasm are often left in the lurch. In fairness to government efforts, however, it can be said that, whatever plans of actions have been formulated do reflect that considerations of early intervention have not been entirely overlooked.

The model which the government seems to favor is to spread throughout the country a network of centers which can provide assessments and diagnostic services, arrange personal aids and appliances and other special education services and many other similar services. It is hoped that the centers especially in the rural setting will be community based and encourage the participation of parents and community members. In order to coordinate, the work of these centers, a national institute of handicapped was envisages and setup. The basic objective of the institute was to coordinate national efforts for prevention of disabilities, to plan and develop an integrated referral system throughout the country by establishing links with the concerned agencies are functioning a village, district and divisional levels. The National Institute of the Handicapped (NIH) was further strengthened following its inceptions. The Institute is presently in operation and is rendering varied services associated with early detection and multi-professional assessment and diagnosis system. The role of coordination assigned to the Institute at the national level. However, still poses a question mark and it is not certain that the far flung centers can and are keeping a close and active liaison with the nucleus in Islamabad. It is too early to say that the models based on network of centers will prove effective to the needs of Pakistan in the field of early child-care. Although some centers have been started, the monitoring process and evaluation have never been strong points of government work and effort. The scarcity of resources and vacillation in government priorities make the matter even worse.

The private and non government effort has also taken interest in early intervention strategies and several ventures have been attempted in this direction. The portage program has held a special fascination for private enthusiasts and some filed work has actually bee or presently being carried out in the country. Amin Maktab in Lahore has initiated a program in progress was initiated in Karachi under the supervision of Ms. Manawer Fatima, a seasoned special educator. UNICEF has also undertaken projects in the field of early detection. Last but not least, the Department of Special Education, Karachi University
is also experimenting with a home based program whereby parents are contracted and invited to the department with their wards. Assessments of the child are carried out and a home education program is developed for each child with a monitoring and follow up arrangement. A research project is also being carried out by the department to assess the effects of some based instruction and examine the possibilities of its replication at other places.

The difficulty with non government programs is that they are still at an experimental stage and have not been able to demonstrate a workable model for the country. A definite need exists of coordination’s between and consolidation of government and private efforts in the field of early intervention in order to evolve a practical, stable and expanding child care system.

REFERENCES