

CHAPTER 1

INTRODUCTION

Background of the study

“In the middle of every difficulty lies Opportunity.” -Albert Einstein

Developmental disorders are widespread among children and their occurrence has risen in recent times. According to World Health Organization report (WHO 7th March, 2023), approximately 1.3 billion people are suffering from some forms of disabilities. These disabilities affect one in six children, which constitutes 16% worldwide.¹

In India, about 2.21% of the population is disabled in one way or another. According to NSS 76th round (National Sample Survey), (Government of India), the prevalence rate in rural areas was 2.3 percent, while in urban areas, it was 2.0 percent. The prevalence rate of disability among males was 2.4 percent, which was higher compared to females, who had a rate of 1.9 percent.² Based on the Statistical Profile (2021)- Persons with Disabilities in India, proportion of intellectual disable person is estimated to be around 0.2%. The prevalence rate of intellectual disability in state of Uttar Pradesh and Delhi found to be 0.2 % and 0.1 % respectively.³ Therefore, it was noticed that India has a high rate of intellectual Developmental disability (IDD) as compared to other forms of disabilities. Among various mental problems, intellectual Developmental disability ranks third following anxiety and depressive disorders in terms of occurrence.⁴

ICD-11 introduced intellectual disabilities as disorders of intellectual and developmental disabilities (IDD) which appears during developmental window. Children with Intellectual developmental disability face many constraints in intellectual functioning as well as adaptive behavior. Intellectual disability is defined by Intelligent Quotient score approximately 70 or below 70. Adaptive skills refer to everyday life skills (such as bathing, dressing, grooming, feeding oneself), verbal proficiency, interpersonal abilities, physical coordination, and activity of daily living, academic skills (reading writing, learning), health and safety. Children with intellectual developmental disability are deficit in these skills.^{5,6,7}

The increased incidence of these neurodevelopmental disorders in children, is ultimately increasing the parental care giver burden as well.^{8,9,10} Disabled children's parents' lives are more stressful than the parents of non-disabled children.^{11,12} The intensity of stress encountered by the caregivers of children with IDD varies depending upon the alteration in the severity level of Intellectual Development Disability.¹¹

Caring for children having Intellectual Developmental Disability is one of the most challenging tasks for the family and primary caregivers, since this type of disability impairs the family functioning which further causes the devastating effect on psychological and physical health of the family members.^{13,14} Some of the research studies also revealed that impaired pattern of family functioning of children with disabilities, is because of maladjustment, lack of security, love, emotional distress, feeling of guilt, poor decision-making strategies.^{15,16,17,18,19}

Family is the most important and secure place, where every child whether he or she is typically developing or have special needs, nurtures, grows and thrives. The birth of child with Intellectual Developmental Disability is the most dreadful situation for any family, as both children with IDD and their caregivers or parents face a lot of problems not only in family but also in society or in community.²⁰ The society has the negative attitude towards their disability which further challenges parents' ability to deal with any the situation; also, they won't be able to use the personal and social resources properly and effectively.²¹ Family including both parents, siblings and others members should be supportive and caring for them, as disabled children require more concern and care than a normal child. It is very pivotal for the family to identify their unique needs and should have proper understanding about the disability of their own child. Caregivers or parents should spend their maximum time with disabled child and should also connect with society, schools, support groups and organizations which will help and support them in catering the needs of their special child.^{22, 23} Moreover, parents have to be confident in their ability to play the parental role so that they can make their child's life successful and self-independent up to some extent.

Basically, children with intellectual disability are deficit in four domains which are communication skills, academic skills, social skills, everyday life skills. But if children with intellectual disability exhibit significant deficits in communication and social skills, then their mothers may experience heightened stress and anxiety compared to others.^{24, 25,26,27,28} Therefore, caregivers of children with IDD face numerous difficulties related to their child's disability, and this can have an adverse effect on their mental health.

A comprehensive literature review conducted by Clement (2018) emphasized the necessity of well-developed parenting support strategies for parents having children with IDD.²⁹ In addition to this, the UNICEF (United Nations International Children's Emergency Fund) proposed a mini parenting master class for parents and caregivers of children with DD. This class highlighted abilities of children rather than their disabilities.³⁰ Furthermore, UNICEF recommended interventions to address the social and behavioral issues faced by children with disabilities.³¹

A cross-sectional research study done by Bunga et al. (2021) to examine the impact of having an ID child on parents. Study involved 100 parents of children with ID attending outpatient services for behavioral issues or rehabilitation at a tertiary care hospital. The findings showed that 56.63% of parents experienced a disability impact related to physical care, 58.87% faced financial problems, and 36.75% reported societal issues. The severity of the child's ID increased the physical care burden and negative thoughts among parents. Despite these challenges, 71.72% of parents did not feel embarrassed by their child's condition, and 67.3% reported positive impacts such as improved tolerance and patience. The study concluded that majority of respondents experienced positive outcomes, such as enhanced self-efficacy and overall life satisfaction, enabling them to provide better care and support for their child.³²

Kumari et al. (2020) conducted a cross-sectional study to evaluate the psychological stress faced by parents of ID children in a hospital setting. The study involved 170 mothers and found that they experienced high levels of stress. The

researchers further suggested by providing clinical services and resources to help parents manage the needs of their children with ID.³³

Parenting Skill Program

In particular, there have been a few studies that focuses on positive parenting intervention and concluded that parenting skill program has an imperative impact on modifying behavior of their IDD children.^{34, 35, 36} It seemed important to researcher to give this intervention to parents as they have the foremost influence on their child from early as well as in late life, doesn't matter to them if the child is normal or a special one. Parenting skill training not only makes the parents confident in their capabilities, but it also helps them to learn daily life adaptive skills and train their child to modify their inappropriate behavior. Moreover, the training program inculcates the positive motivation, guidance and zeal in parents to bring the child on right or appropriate track and also improves the family interaction related to caring IDD child.³⁷

A few studies inferred that the training programs are necessary for both parents and children with IDD viz. according to one study, parents of mentally retarded children are more prone to stress, anxiety and depression and it has been found that the various training techniques like behavioral technique (role play, modeling, shaping, feedback, practice), Triple P Program (Positive Parenting Program) are effective for the parents of mentally retarded children.^{38,39,40,41} Also, McIntyre Laura Lee (2008) figured out that parent training program was very effective for children (2 to 5 Years) with developmental disability and also helpful in decreasing the inappropriate parent- child relation as well as behavioral problem in children.⁴²

Hence, after doing extensive review of literature related to parenting intervention programs, researcher designed a training program in order to improve and strengthen the parenting skills of parents of children with IDD. This Parenting Skill Training Program is a psycho educational training program which consists of 12-week sessions having duration of 45 Minutes for each session. It was based on the various behavioral techniques which aided the parents to develop necessary skills to bring modification in their own child's behavior confidently, improve their self- efficacy and mental well-being.

In this regard, the World Health Organization has introduced a new approach called the Caregiver Skills Training Program (CST), specifically designed for families with children who have disabilities. The program's objective is to address the existing treatment gap by empowering caregivers to acquire the essential skills needed to boost up their children's adaptive behavior, interpersonal, communication skills and thereby reducing the challenging behavior of their children with IDD. Additionally, it aims to promote the mental well-being of these parents.^{43, 44, 45}

A cross-sectional study conducted by Irawati SS and colleagues in 2023 highlighted the implementation of parenting programs and behavioral management therapy, incorporating the ABC approach (Analysis Behavioral Consequences Approach), as a means to enhance the parenting skills of caregivers with children having IDD. This approach aimed to empower parents to assist their children with IDD in strengthening their adaptive abilities.⁴⁶

Need for the study

Caring for children with IDD is a challenging, as they are very unique and special children who need more care, affection and concern which makes them the biggest responsibility of their parents. Children with IDD have deficiency in their adaptive skills viz. not able to communicate, socialize with others, not able to perform academic task, even not able to complete their everyday life skills such as how to brush the teeth, get dressed, groomed, fasten the laces of shoes etc.⁶ Parents often experience anxiety, depression and psychological distress because they are unable to cope up with the situations related to their special children. Additionally, they are subjected to stigma, discrimination and neglect or isolation by the society, due to which they are having very less expectations to raise their child in such environment. Hence, parents need to remold their expectations and confront enthusiastically all the challenges coming their way in rearing and caring of their child.^{47, 48, 49}

Few studies concluded that the training programs are necessary for both parents and IDD children viz. Machalicek et al. (2015) found that the parents of children with ID were more prone to stress, anxiety and depression and they found that the various training techniques like behavioral parent technique (role play, modeling, shaping, feedback, practice), Triple P Program were effective for the parents of ID children.^{50,51}

Also, McIntyre Laura Lee (2008) observed that parent training program was very effective for children (2 to 5 Years) with developmental disability and also helpful in decreasing the inappropriate parent- child relation as well as behavioral problem in children.⁴²

Derks S et al (2022) emphasized the significance of engagement of activity-based games to enhance the adaptive and cognitive skills of children with ID and ASD.⁵²

Kirkpatrick et al. (2019) carried out an extensive literature review to evaluate the effectiveness of combined parenting and sleep intervention for ID and ASD children. The findings showed that out of eleven, nine studies observed a reduction in sleep problems among ID and autism spectrum disorder children.⁵³

Sun et al. (2022) conducted a comprehensive literature review to examine the behavioral skill training intervention for caregivers of individuals with IDD. They analyzed 17 research articles and found that both caregivers and individuals with IDD showed significant improvements following the intervention.⁵⁴

Researcher seemed it is crucial to give this intervention to parents as they have the foremost influence on their child from early as well as in late life, despite the fact that their child is normal or a special child. Parenting skill training not only makes the parents confident in their capabilities but also, they will be able to teach and train their child in their daily life adaptive skills and also can modify inappropriate behavior of child enthusiastically. This training program inculcates the positive motivation, guidance and zeal in parents to bring the child on right or appropriate track and also improves the family interaction related to caring IDD child.

Research Statement-

Effectiveness of Parenting Skill Program on child's adaptive behavior, parental self-efficacy and mental well-being among the parents of children with Intellectual Developmental Disability in selected Special Schools of Delhi.

Aim-

To strengthen parenting skills, parental self-efficacy and mental wellbeing and thereby improving the child's adaptive behavior.

Objectives of the study-

Primary Objectives

1. To assess the effectiveness of Parenting Skill Program on
 - a) Child's Adaptive Behavior.
 - b) Parental Self- Efficacy.
 - c) Parental Mental Well-Being.

Secondary Objectives

2. To determine the correlation between child's adaptive behavior and parental self-efficacy and mental well-being before intervention.

Hypothesis-

The hypothesis would be tested at <0. 05 level of significance.

H₁- Adaptive behavior score of children in experimental group would be significantly better than the control group after implementation of parenting skill program.

H₂- There would be significant improvement in parental self-efficacy score in experimental compared to control group after administration of parenting skill program.

H₃- There would be a significant improvement in parental mental well-being score in experiment group compared to control group after implementation of parenting skill program.

H₄- Parental self-efficacy and child's adaptive behavior would be correlated.

H₅- Parental mental well-being and child's adaptive behavior would be correlated.

Operational definition of terms:

Effectiveness

Effectiveness is the measure of how well an intervention achieves its goals, produces desired outcomes and brings about intended changes reliably and impactfully. In this study, effectiveness refers to the effect of implementing a parenting skill program on parents to improve behavior of their children and enhance their own parental self-efficacy and mental well-being as measured by Vineland Social Maturity Scale, Parenting Sense of Competency Scale, and the Warwick-Edinburgh Mental Well-being Scale.

Parenting Skill Program

It is a psycho educational training program consisting of 12-week sessions, each lasting 45 minutes. The program is based on the various behavioral techniques which helps the parents to develop necessary skills so that they would able to bring modification in their child's behavior confidently, improve their own self- efficacy and mental well-being.

Child's Adaptive Behavior

It's the ability of the child with IDD to perform the everyday life skills independently such as self-help skills i.e., eating, dressing, communication, self-direction, occupation, socialization and locomotion and according to his/her age as reported by his/her parents. It is measured by Vineland Social Maturity Scale.

Parental self-efficacy

It refers to the parent's belief in their own ability to modifying their child's adaptive behavior measured by parenting sense of competency scale.

Parental Mental well-being

It refers to the state in which parents are able to realize their own potentials to manage their daily life stress, thereby living a happy and successful life with child having intellectual Developmental disability as measured by Warwick-Edinburgh Mental Well-being Scale.

Children with Intellectual Developmental Disability

It refers to those children who have impaired adaptive behavior and diagnosed with mild (50-90 IQ) or moderate (35-50 IQ) intellectual developmental disability on formal IQ assessment done by Clinical Psychologist which is obtained through school records.

Parents

It refers to mother and father who are having a child with mild or moderate intellectual developmental disability.

Special Schools-

Refers to schools which are registered under Rehabilitation Council of India and have special facility for educating children with intellectual Developmental disabilities and coming under Union Territory of Delhi.

CONCEPTUAL FRAMEWORK

The conceptual framework of this study is according to Health Promotion Model (HPM) which was developed by Nola J. Pender in 1982 and was revised in the year 1996. Its aim was to teach the parenting skill program to parents having children with IDD and to develop necessary skills so that they will be able to bring modification in their own child's behavior confidently, improve their self- efficacy and mental well-being.

The Health Promotion Model explains the multidimensional essence of the person as they interrelate with their surroundings to pursue wellbeing.⁵⁵

The health promotion model acknowledges individual uniqueness and experiences as factors influencing behavior. It emphasizes the significance of specific factors, such as knowledge and motivation in shaping behavior, which can be influenced by nursing interventions. The desired outcome is improved health behavior across various aspects, including better health, enhanced cognitive abilities, and an improved quality of life throughout development. However, competing conditions and choices may hinder intentional health promotion efforts, impacting the final behavioral result.

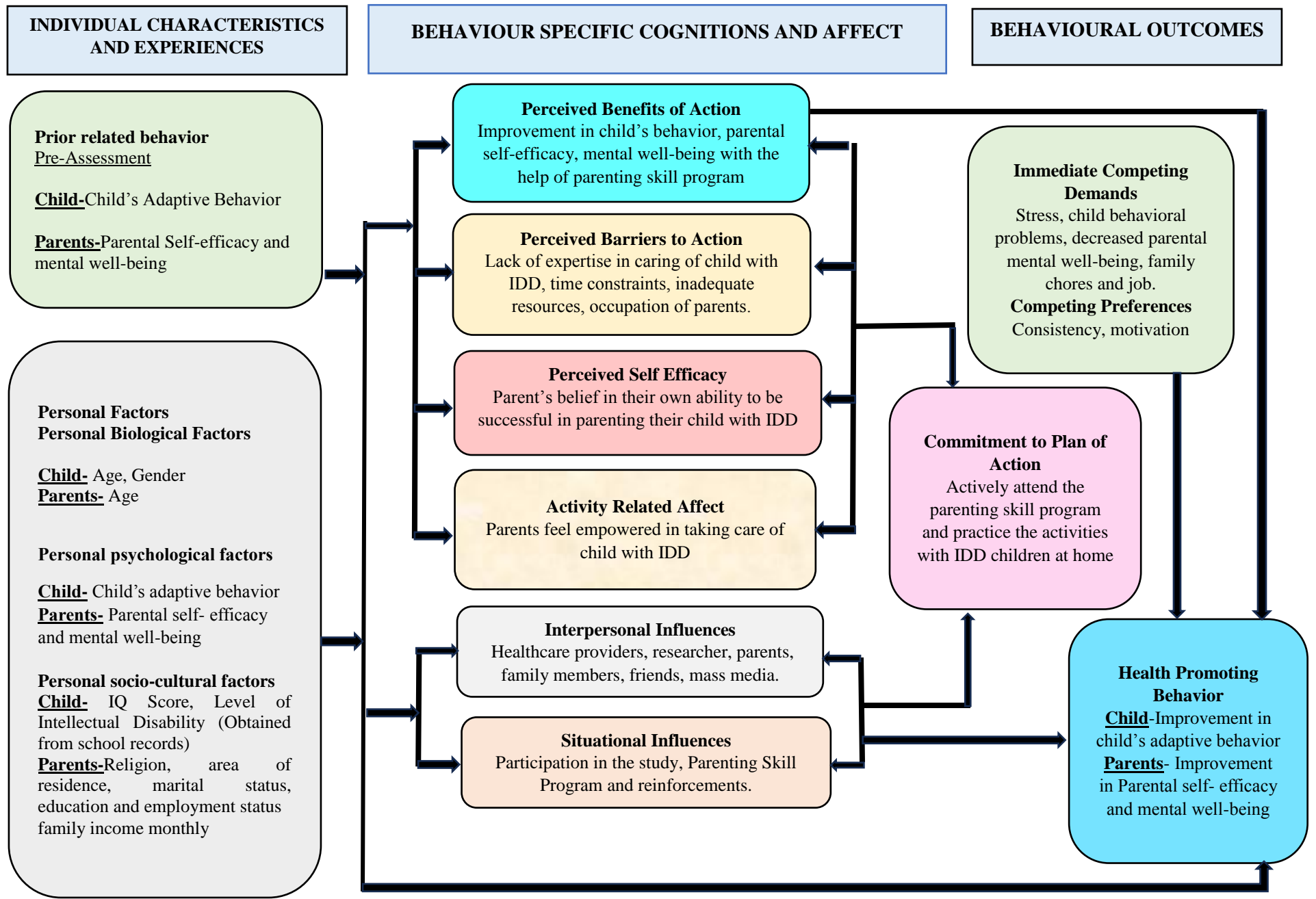


Fig. 1: Health Promotion Model (HPM)

(A) Individual Characteristics and Experiences

Understanding individual traits and experiences involves two dimensions:

(i) Prior related behavior

Prior related behavior refers to an individual's past actions and experiences that influence their current health behavior. It recognizes the significance of previous behaviors in shaping and predicting a person's choices and actions related to health.

In the context of this research, prior related behavior includes child's adaptive behavior, self-efficacy and mental wellbeing of parents which were measured by investigator before intervention.

(ii) Personal Factors

Personal factors play a crucial role in shaping an individual's overall well-being, and in the context of this research, these factors are classified into biological, psychological, and socio-cultural dimensions.

In terms of biological factors, child's age and gender, along with parents' age, are key determinants. Psychological factors include the adaptive behavior of child, self-efficacy and mental well-being of parent. Additionally, socio-cultural factors include child's IQ score and level of intellectual disability which were obtained by researcher from the school record. For parents, socio-cultural factors include aspects such as religion, marital status, area of residence, monthly family income, education, employment status.

B) Behavior specific cognition and affect

It serves as a crucial core for intervention due to their adaptability through targeted measures. This domain encompasses various key components that shape an individual's actions. These components include the benefits and barriers to action as perceived by person, perceived self-efficacy, activity related effect, situational and interpersonal influences. Recognizing and addressing all these specific elements can significantly enhance the effectiveness of interventions resulting in promoting positive behaviors and fostering overall well-being.

(i) Perceived benefits of action

Expected health benefits influence the plan of a person to take part in health promoting behavior and encourage regular healthy practice. In this study, anticipated positive outcome for participating in Parenting skill program administered by researcher to parents of children with IDD were improvement in child's adaptive behavior, self-efficacy and mental wellbeing of parents.

(ii) Perceived barrier to action

An individual's perception regarding certain factors which may act as a barrier. In this study, lack of expertise in caring of children with IDD, time constraints, inadequate resources financial constraints, occupation of parents acted as perceived barrier for parents to participate in parenting skill program administered by researcher.

(iii) Perceived self-efficacy

It refers to the determination of a person to successfully perform the behavior important for achieving the desired outcome. In this study perceived self-efficacy are parent's belief in their own ability to be successful in parenting their child with IDD after receiving parenting skill program.

(iv) Activity related Affect

The feelings of individuals which occur before, during and after an activity may have an impact on their behavior ensuring whether an individual will maintain the positive behavior in future. In this study, activity related affect means that before attending training program parents may feel inadequate but after attending the program, they feel empowered in taking care of children with IDD.

(v) Interpersonal influences

These are the individual's perception regarding behavior, belief or attitude of others. Family members, peers' group and health care professionals can influence a person's health promoting behaviors. In the context of this study, family members, friends, peers, healthcare professionals might have acted as interpersonal influencing factors contributing to modification of behavior of children with IDD

(vi) Situational Influences

This refers to the perception of a person regarding availability of facilities for promoting health, its characteristics, availability and how it directly and indirect affect the health. In context of present study, it refers to how parents perceive benefits of parenting skill

program, their willingness to participate in parenting skill program, and developing parenting skills to take care of children with IDD.

(C) Immediate Competing Demands and Competing Preferences

It refers to behaviors over which individuals have limited control because of external factors such as family or work responsibilities. In context of present study, the competing demands are stress, behavioral problems of children, family chores and occupation.

(D) Commitment to Plan of Action

It refers to commitment of parents to actively attend parenting skill program administered by researcher, practice the techniques learned during the program to bring improvement in self- efficacy and mental well-being of parents and child's adaptive behavior.

(E) Behavior outcome

The outcome of health promoting behavior is to improve health and cognitive functional capability of person, better quality of life at all phases of development. In the context of this research, it refers to positive changes reflected in adaptive behavior of children observed by parents after they applied techniques learned during parenting skill program administered by researcher.

Assumptions: The study assumes that –

1. The sample will be true representation of target population.
2. Parents may not have the sufficient knowledge and skills in managing the behavior of children with IDD.

3. Parents of children with IDD will adhere to parenting skill program.

Delimitations-

The study was delimited to

1. The selected Special Schools of Delhi.
2. Child's adaptive behavior as reported by the parents.

Summary:

This chapter covered the study's introduction, need, problem statement, objective, purposes, conceptual framework, operational definition, hypothesis, assumptions and delimitations.