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Research Paper



Siblings of Differently Abled & Intellectually Disabled - A Study on their Mental Health

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ABSTRACT

Mental health is a state of mental well-being that enables people to realize their abilities, cope with the stresses of life, and contribute to their community. Mental health exists on a complex continuum, experienced differently from one person to the next. Mental health is a basic human right. Many individual, social and structural determinants may combine to protect our mental health. Risk can manifest at all stages of life, but those that occur during early childhood, are particularly detrimental. Most people do not develop a mentally ill condition by mere exposure to a risk factor. On other end, in certain Tamil culture families, parents & siblings of differently abled, with availability of differently abled child as risk factor, develop mentally ill condition. This study by the researcher describes, qualitatively on what role attitude, plays on determining mental health. The study also focuses on identification of their strengths and difficulties using standardized tool, 'Strengths and Difficulties Questionnaire' (Goodman) a brief behavioural questionnaire that can be completed by parents for their opinion on siblings.

Keywords: Mental Health, Attitude, Family of Differently Abled, Exposure to Risk, Coping, Strengths & Difficulties.

isability population studies suggest that there are at least 164 million children with disabilities in India, census describing 660 thousand more than the number recorded in 2001. International classification of functioning, Disability & Health (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. "United nations declaration on rights of Mentally Retarded persons" describes, that Intellectually Disabled person should live with his own family or with his foster parents and participate in different forms of community life. The family with which they live should receive assistance. If an institutional care becomes necessary then it should be provided in surroundings and circumstances as much closer as possible to that of a normal lifestyle. Hence, parents are the pillars of any type of differently abled are identifiable.

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Many parents of differently abled children undergo emotional turmoil, because of the ongoing challenges of special child. With parents, siblings also meet with unexpected, uninformed, hidden strains for life time. Though most of the problems faced at home are tackled by elders, the children feel helpless in meeting the demands of peer group relationship. These children exhibit behavior problems, become underachievers at school, and later indulge in antisocial activities for gaining attention in society. Hence, to detect whether siblings are at high risk of mental health problems was the intention of this study. Mental health problems carries a root cause as always early identification is better, teachers and parents assessment on the siblings was used.

Aim &Objectives

- To identify normal school going children in families of differently abled.
- To analyze their views on whether the presence of differently abled child in family makes any difference for them (attitude)
- To categorize in qualitative terms, the difficulties faced by siblings on prosocial behaviour, emotional problems, hyperactivity, peer problem, conduct problem using a valid tool, like strength difficulty questionnaire.
- To do Interpretation, of the received data with mental health.

Need for the study

American Psychological Association, in 2008 published, those siblings of mental illness are more likely to experience depression during any age, in their life time. Dr Emanuele, describes that, younger brother or sister of the affected differently abled child tries to mimic negative behaviours, at their childhood. Children with comorbid developmental or learning problems and mental ill-health typically have lower self-esteem (Stevenson & Romney, 1984). Symptoms of anxiety and depression (Boetsch et al,1996) are also common in children with dyslexia. Children with developmental language disorder (DLD) are at of emotional problems and depressive disorders (Goh et al,2013). Poorer relationships with family and peers, with elevated levels of aggression is also seen (Kim et al,2000) compared to children with only one condition. Providing these children with timely support is therefore the need for an evaluation tool for identifying symptoms of mental health disorders.

Related Studies describe, only about 20% of children are identified and treated for mental health problems (Offord et al., 1987; Burns et al., 1995; Leaf et al., 1996; Meltzer et al., 2000).

Hence, in the study area, researcher finds that early identification by professionals can help identify symptoms relevant to mental health for siblings of differently abled.

Parents and Professionals

Nowadays many professionals help to lessen the burden of family, on overall aspects of disability. Parents are active partners in implementing professional advice. Better identification of problem related to their differently abled child, framing short and long therapy goals are done, if parents are cooperative. ATTITUDE of family comprising parents, siblings, and for some individuals, grandparents also plays a vital role in such rehabilitation. An attitude is a partially permanent set of feelings that refer to what the person feels in relation to an attitudinal subject. Attitude focuses on beliefs, expectations, opinions held by a person in relation to an attitudinal subject. This simple explanation is given in text, "Attitudes – Introduction and scope" by D Albarracín, BT Johnson, MP Zanna. Around the

world, different opinion such as sympathy, pity exists towards differently abled. We term it as ATTITUDE in a professional word. Qualitative measurement of such attitude can enhance finding of the necessary deficits in particular for the person rather than describing in general like protective attitude, neglect attitude.

Since attitudes are learned, it can be assumed that they are learned in particular experiential contexts. Thus, one would predict the attitude that non-disabled persons have toward disabled persons would be a function of their past experiences with disabled persons. Among these experiences would be the extent of their contact with disabled individuals and also the extent to which they had specific "educational" experiences designed to provide them with information about disabled persons.

Attitude of parents are assessed

"An attitude is, idea charged with emotion which predisposes action to social situations" (Triandis, 1971, p. 2). At present, disability is understood from a perspective as the interaction between persons and their environment. The surroundings is important for understanding attitudes as social construct. As per definition, Attitudes are learned pre-dispositions to respond in a favourable or unfavourable manner to a particular person, behaviour, or belief. Thompson; 1982, Yamamoto; 1971 say that able bodied people are not clear about how they should behave when disabled people exist with them. Murphy (1990) explains disability as a 'disease of social relation' between disabled and the able-bodied people. When we analyse parents of differently abled, first, they deny that their child is having an intellectual disability. This denial becomes acceptance, when the professionals can coordinate the medical history & clinical findings, of the differently abled person. But, so much of information to make the family understand Disability, from professionals also creates a neglect attitude in them, without trying suggested THERAPY programs. They show a less turn over to therapy settings at essential time and age of the child. Hence, it is much essential to make appropriate assessment of attitude, get cooperation from the family.

Attitude on disability

WHO (2011) states that one billion people in the world live with some form of disability and almost 200 million experience considerable difficulties in their daily life. Importance of parents, sibling support in achieving therapeutic goals for differently abled is documented in many studies. If the social group of healthy child is bullying the child for presence of differently abled person in their family, their support, to achieve betterment of differently abled may get reduced. Hence, attitude toward the disabled including investigations of prejudice, acceptance-rejection, and individualized versus stereotypical attitudes can be done.

Attitude towards disabled persons (ATDP) scale is used

To measure attitude with the disabled, many valid recent scales of assessments are available. But using ATDP was easy as suitable to my study group of parents and siblings of differently abled. Some instruments were used to measure the attitudes of the non-disabled toward differently abled persons. Other instruments in psychology were used to measure the attitudes of disabled persons, toward their disability, or to provide a general measure of their adjustment. Literature shows, two studies used sentence completion tests for eliciting attitudes toward physical disability (Granofsky, 1955) or chronic illness (Ford, Liske &Ort, 1962). Granofsky (1955) also used projective techniques similar to the TAT in his study of the effect of contact in changing the attitudes of women toward disabled men.

Attitude measured by ATDP

ATDP was first reported at 1959.Measuring attitude was developed as a scale, by Yuker et al. APA published this scale in 1960.ATDP is relatively short, easy to administer, score and interpret. ATDP collects the positive and negative scores and arrives at results. It correlates highly with the regular scoring procedure.

Advantage of using ATDP scores, is, it measures two types of attitudes. ATDP could be interpreted in terms of the prejudice of non-disabled persons and the attitudes of disabled persons toward themselves. A score that is highly relative to other scores would indicate that the respondent perceives differently abled persons as being relatively similar to normal persons, whereas a score that is low indicates that differently abled persons are perceived as being different. This scale, measures written responses and not behaviour of the respondents.

Interpretation of Scores

Three forms of the ATDP is available. The Form 0, has 20 items. Form A, Form B describes another 30 items each. They are presented in Likert format with six response categories ranging from, "I Agree Very Much" to "I Dis-agree Very Much." Scores range from +3 to -3. The scale takes 10 to 15 minutes to administer, and is relatively easy to score. Scores range from 0-120 on form O and 0-180 on Form A and form B. After summation of scores, High scores, (positive)indicate perceiving their child/sibling disabled as basically the same. Negative score indicate perception as different from the non-disabled.

Mental Health of Siblings

As per Diagnostic Statistical Manual classification, mental disorder is some kind of "mind disease." As Thomas Szasz pointed out more than 50 years ago, minds are not biological, and in a literal sense, cannot be afflicted by diseases. Most of the disorders listed in the DSM, therefore, fall into two likely categories:

- a) Everyday problems in living that warrant professional attention but are not diseases, and
- b) Suspected brain diseases whose etiologies may one day be uncovered but currently remain unknown.

In this classification, we can understand, siblings of differently abled best fit in both subdivisions.

Positive Attitude & Mental Health

Positive attitude brings positive thoughts. Positive attitude people, as per researches available, focus on challenges as opportunities. Strengths can be appreciated, positive coping skills can be developed, with them. Instead of indulging unhealthy coping like substance abuse, & alcohol abuse (Negative attitude people do) positive people stay away from many stress related mental health conditions.

Positive Psychologist Dr. Fredrickson has spent many years, researching, benefits of positivity, on mental health. Fredrickson proposes three positive emotions are connected to positivity. These positive emotions according to her, reverse the negativity and build up psychological resources. They are forgiveness, gratitude, emotional resilience. positive thinking and positive emotions broaden and build our resources and skills, opens up to possibilities (Fredrickson, 2004). There are many other benefits of cultivating a positive mindset, including better overall health, better ability to cope with stress, greater well-being (Cherry, 2017A). According to a 2012 study on primary school children, only 38% of them

had a Disability Equality Scheme in place and only 30% included a plan to "promote positive attitudes towards disabled people" (Beckett & Buckner). Further, 76% of schools reported that their staff had not received any training in the promotion of positive attitudes towards students with disabilities. In such a way, advanced focuses are available nowadays. WHO member States are committed to implement Comprehensive mental health action plan (2013-2030), which aims to improve mental health by strengthening effective leadership and governance, responsive community-based care, implementing promotion and prevention strategies, and strengthening information systems, evidence and research.

Family

Characteristics of family like nuclear or joint family, area of residence such as rural or urban area, perceptions of parents and grandparents related to religious practices can also influence the attitude. Turnbull (1986) has mentioned that family undergo stress at each developmental stage of child with disability from diagnosis of the condition, availing medical services, family adjustment towards stigma of disability in early years. Adolescence brings additional problems of sexuality, uncertainty about future. Social problems experienced by these parents include, 'reduced income' due to lack of concentration on skill development of income generating activity. Epel et al,2004 describes that, mothers of differently abled experience very high stress levels, potentially making them more susceptible to depression and anxiety, and cellular ageing beyond their years. The mental health issues experienced by mothers of children with disabilities have been assumed to be due to grief and sadness related to the child's disability (Green, 2007).

Siblings and Differently abled

As Powell & Ogle, (1985) suggests, sibling relationship is child's first social network and are the basis for all interactions with people outside the family, attitude of sibling play an important role. Parents should be the mediators between differently abled person and the other "normal siblings". The assumptions of professionals regarding what the child is capable of, needs to be discussed with siblings also. While seeking professional advice, siblings can be taken along with them. Parents can act as teachers to monitor the siblings on day to day happening to get rid of academic failure, poor social relationships, negative self-esteem. Siblings in early years exhibit behaviour problems to seek parental attention, they provoke temper tantrums to make parents be with them.

Negative Attitude may be from peer group of the siblings

Compared with other forms of stress, stress triggered by one's social network (peer group) persists over a longer period of time (Bolger et al, 1989). Negative interactions with social network apparently arouse more stress in individuals (Zautra et al, 1994). As mentioned by (Lincoln, Chatters & Taylor, 2005) negative interactions may hinder goal directed activity, erode perceived Self-Efficacy, disrupt problem solving, pose a threat to self-esteem, and interfere with use of resources. If many negative attitudes are present with siblings, in accepting differently abled as a play partner or in identifying them along with disabled person, it moulds them harder. Depending on their attitude they show either positive or negative attitude toward disabled, may or may not help in daily activities, may or may not have a parallel play, may or may not give a speech training, if needed, to them. Social models of childhood disability emphasize the importance of the physical, cultural, social, economic, and attitudinal context within which the child lives as a key in determining a child's access to life enhancing opportunity (Colver, 2005;world health organization, 2001) other demographic and family factors such as low income, single parent status, and lower

parent education are also strongly related (Law et al., 2006; McGuire, Crowe, Law, & VanLeit, 2004; Morris et al., 2006; Wright et al., 2008)

Is there an influence of Attitude, on personality of siblings

Attitude is dynamic whereas personality is combination of mental behaviour, traits or qualities like thinking, feeling, and emotions. Attitude may change but personality may not change over as it comprises of psychological traits also. When the normal siblings, at their developmental stage, perceive, absence of parental care, it can influence their personality.

Antisocial activities in Children as given in literatures

Antisocial behaviour is not only violence or intent to cause harm to other children. It includes, stealing, violence towards animals, litter problem (disposing waste, in unwanted location) showing their presence with peer group in noisy behaviours.

Moreover, when a personality disorder is present, the treatment of other coexisting psychiatric or medical conditions is frequently more complicated, lengthier, or less successful. It is advisable that, siblings attitude needs to be explored.

REVIEW OF LITERATURE

The studies done during 1960s, as reported by Yuker, Block and Campbell, shows that persons with high anxiety tended to have less accepting attitudes. one study reported by Whiteman and Lukoff, observed that, "A significant relation was found between an anxiety index consisting of selected items from the Taylor Manifest Anxiety scale and the Emotional Traits of the Blind Index". The results of this study is, persons with high anxiety, tended to be less accepting of differently abled persons. Moreover, two studies of non-disabled persons (Knitter, 1963; Human Resources, 1964) have been reported showing no significant relationship between intelligence and attitudes toward the differently abled. A study done on mental health of parents of children with a developmental disability in British Columbia by Sandra Maureen Marquis et al provides population-based evidence that having a child with a developmental disability is associated with parents having depression or another mental health problem.

Many literatures have more than 30 definitions of the term attitudes (Rao, 2004). In Asia, America, African countries, attitude towards Intellectual Disability is less understood. Kraus (1985) found that attitudes significantly predict behaviour. Study of attitudes is necessary to educate the sibling, regarding the exact condition of differently abled & the essential support they need to offer parents, grandparents in handling the situation. Although there is still no universally accepted definition, most researchers agree on the assumption that attitudes are constructs with affective, cognitive, and behavioral components (Olson & Zanna, 1993). In old terms, attitude is defined as "a mental and neural state of readiness, organized through experience, exerting a directive or dynamic influence upon an individual's response to all objects and situations with which it is related". In the past decade, many such studies are available for attitude towards differently abled persons.

METHODOLOGY

Study setting

Study sample includes, 30 siblings of various types of differently abled people. Number of participants(siblings) in each category is Visual disability (4), Auditory disability (2), locomotor disability (8) (PPRP, Cerebral Palsy) and MR, Down's syndrome (16)

Selection of Participants

By Randomized control trials, researcher included, thirty siblings as participants. They were belonging to age group, 11 to 17 years. All participants were undergoing mainstream education, in nearby schools.

Study sample included both gender participants.

Attitude towards disabled persons questionnaire was administered to siblings and response collected. This is done to analyse their views on whether the presence of differently abled child in family makes any difference for them (attitude)

Strengths and Difficulties Questionnaire by Goodman for identifying strength & difficulty was also administered to parents, to assess those siblings in need of mental health services.

Description about Strengths and Difficulties Questionnaire (SDQ)

SDQ is widely used international standardised instrument measuring child behaviour. The instrument is developed by United Kingdom child psychiatrist Robert N. Goodman. It is available in a variety of versions for different age groups and types of respondents (parents, teachers or the child itself) and is translated into 70 languages, for its widespread application. It consists of 25 questions, which are divided between five scales with five items each: 1) emotional symptoms, 2) conduct problems, 3) hyperactivity/inattention, 4) peer relationship problems and 5) prosocial behavior. The first four scales added together generate the Total Difficulty Score. The scores are made by noting down the responses,

- 0 for Not True,
- 1 for Somewhat True.
- 2 for Certainly True obtained by participants in each.

Description of subcomponents

Responses in the questionnaire were separately tabulated, as given below.

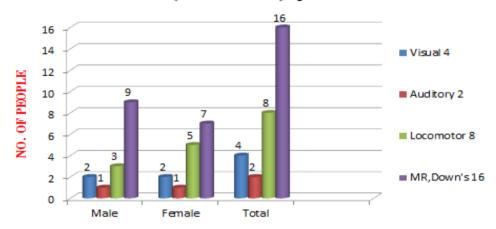
•	Prosocial Behavior	1,4,9,17,20
•	Emotional Problems	3,8,13,16,24
•	Hyperactivity scale	2,10,15,21,25
•	Peer Problems	6,11,14,19,23
•	Conduct Problem	5,7,12,18,22

SDO can give an indication, of whether sibling is likely to have significant emotional or behavioural disorder and what type of disorder it is.

Findings from the study

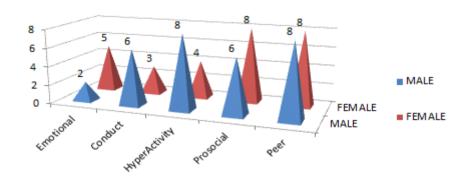
Graph 1-Participants of Visual, Auditory, Locomotor, Intellectual Disability & Down's syndrome siblings

Siblings of Differently Abled (11 to 17) years

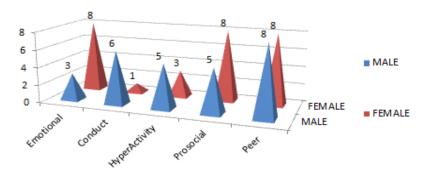


Graph -2 showing SDQ for participants of 11 to 14 years

SDQ scores for Individual Components 11 TO 14 years



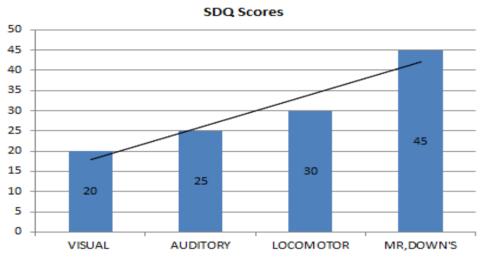
Graph -3 showing SDQ scores for participants of 15 to 17 years SDQ scores for Individual Components 15 TO 17 years



From the study, it was found that PEER problem scored the maximum in both female, male of 11 to 17 age group.

Irrespective of age, hyperactivity component scored second, Prosocial component third, conduct scored fourth, respectively. Male siblings had top score with least score in emotional component. Prosocial carried max score with emotional for females till 17 years. The study reveals that when the siblings have (ID)Mental retardation & Down's syndrome the day to day demands on normal sibling was more when compared to other form of disablement. The family each day pulls out different problems.

For those siblings of visual, auditory, locomotor disablement, total score was low, compared with siblings of Intellectual Disability. SDQ Score was 20 for siblings of visual disability, 25 for auditory disability, 30 for locomotor disability and it is 45 for siblings of intellectual disability.



Total SDO scores for siblings participated in the study

RESULTS

Healthy child (siblings) of differently abled children, belonging to visual, auditory, locomotor, Mental Retardation & Down's syndrome type of disablement were included for the study. About 30 male & female siblings, of age group 11 to 17 years participated, with their parents' consent. They were administered ATDP Questionnaire and the results tabulated.

Each scale was shown with the child's score, and the Total Difficulty Score was stated. The child's scores were automatically classified as" normal"," slightly raised", "high" or "very high" Thus, the attitude of family, towards differently abled child in Cuddalore district was analysed, the results were simply tabulated.

Findings from ATDP assessment of sample

In the sample selected by the researcher, People who are educated (parents, siblings) in differently abled families, have increase in acceptance of differently abled children. The relationship appears to be curvilinear, meaning that there is an increasing positive attitude with education and at a specific point, when work pressure of parents is added, the attitude gets low scores. Mothers and female siblings score generally high on ATDP than do fathers and male siblings.

Findings from SDQ assessment of sample

The siblings assessment done with SDQ reveals that irrespective of type of disability of their siblings, every normal brother and sister is having a drawback. When categorized as girls and boys, scoring of emotional problem, Prosocial behavior, is more for females. Hyperactivity, conduct scoring was more for male siblings. By SDQ calculations, Internalizing score and Externalizing scores are to be made. Internalizing is by adding emotional & peer score. Externalizing score is by adding conduct score and hyperactivity score.

Total Difficulties Score is generated by adding scores from all the scales except the prosocial scale. The score of participants ranges from 0 to 45, which indicated high need of help for their difficulties experienced.

Codification (code)

Code means, a systematic collection of statues, body of law, so arranged as to avoid overlapping & inconsistency. In India, Code of Manu existed from ancient times. In 1883, Indian law commission, with Lord Macaulay as chairman, drafted a number of codes, such as Indian penal code, civil procedure code, criminal procedure code. Many advantages exists by this codification. Law is made easy & accessible to everyone. Law no longer remains vague. To codify means to arrange laws or rules into a systematic code. This process does not necessarily create new law, it merely arranges existing law, usually by subject, into a code. This form is codification.

The Centers for Medicare and Medicaid Services (CMS) and the National Center for Health Statistics (NCHS), Federal Government's Department of Health and Human Services (DHHS) are departments within the United states, provide the guidelines for coding, Clinical Modification (ICD-10-CM). These guidelines are a set of rules, developed to accompany official instructions provided within the ICD-10-CM itself. Adherence to these guidelines when assigning ICD-10-CM diagnosis codes is required under the Health Insurance Portability and Accountability Act. A joint effort between the healthcare provider and the coder is essential to achieve complete and accurate documentation, code assignment, and reporting of diagnoses and procedures. The guidelines are organized into sections. It is necessary to review all sections of the guidelines to fully understand all of the rules and instructions needed to code properly.

They are used for proper treatment and matching medical charges correctly for any medical services. In United States, ICD codes are overseen by (CMS) and the (NCHS), standardized treatment for a medical issue is delivered and that medical expenses are reimbursed.

The following is the appropriate coding, as found in website information for family of differently abled.

- The ICD-10 code range for Persons with potential health hazards related to family and personal history and certain conditions influencing health status is Z77-Z99.
- ICD-10-CM Code for Inadequate parental supervision and control **Z62.0**
- Parent-biological child conflict -**Z62.82**
- This includes, current and past negative life events in childhood current and past problems of a child related to upbringing in the family.
- ICD-10-CM Code for Family history of intellectual disabilities Z81.0

History codes (categories Z80-Z87) may be used as secondary codes if the family history has an impact on current care or influences treatment.

The ICD-10 Code range (Z77-Z99), is used for Persons with potential health hazards related to family and personal history and certain conditions influencing health, exposures hazardous to health, Other specified health status, Long term (current) drug therapy, Family history of primary malignant neoplasm, Family history of mental and behavioral disorders, Family history of certain disabilities and chronic diseases (leading to disablement).

USE of Coding in my study sample

Many mental health symptoms though present in the families of differently abled, these members don't access treatment due to lack of awareness. Their suffering relating to mental illness is not identified for them. Moreover, stigma attached to visiting a PSYCHIATRIST exists in most of my study participants. When the coping skill training is given to them, they readily accepted & practiced as per the instruction of researcher. This training was viewed as very good alternate, which they missed to learn till date. Their pathetic economic condition, also makes them, to avail therapy services as needed for the differently abled and most of the parents & sibling focused their requirements secondary.

Use of coding, hence is felt as essential, to help them access mental health services. Professional codes can help capture physician and other clinical services with a code for billing. These codes can form the documentation in siblings medical record. The medical services offered for differently abled can be applicable to family also.

CONCLUSION

As described in this study, the researcher focuses on identifying mental health issues as applicable to siblings of differently abled, strengthening mental health care through coping, so that the full spectrum of mental health needs is met. We as professionals come across, the siblings of differently abled children who lead a "slightly deviated" normal life. This may be because of their underlying family problem. By subcomponents, If children lack PROSOCIAL behavior and peer relationship voluntary behaviour to Help others and receive help in need may be affected. Handling emergency situations at family, with help of relatives, lack of adjustment may be presented. Notable sub scores in peer problem, lack of adjustment among friends were presented in my study group participants. It seems that, if not identified at the vulnerable age of 11 to 17 years, the risk of developing psychological and emotional problems are high in future. Hence by this study, I conclude, that identification of strengths and difficulties of siblings is very essential.

While treating mental health symptoms, it is also necessary to include CODING. By finding this information, parents or siblings may access appropriate, relevant medical services for mentally ill symptoms. Hereafter, when, we as professionals come across the siblings of differently abled children who lead a "slightly deviated" normal life, it is essential to make use of our professional protective attitude to help these needy people. Moreover, we can understand that parents and siblings with positive attitudes toward the differently abled score lower in measures of *need for aggression* or *expression of hostility* than those with negative attitudes. Availing medical services earlier, & government schemes for differently abled, family of differently abled persons can make lot of difference in their quality of life.

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Conflict of Interest

The author(s) declared no conflict of interest.

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