

Relationships of Adult Siblings with Intellectually Challenged Children: Their Roles and Responsibilities

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Abstract

There is very little research done in Pakistan on adult sibling relationships, despite of the importance these relationships have in the life of children with intellectual challenges. Thus, the purpose of this qualitative research was to investigate the perceptions of adult siblings about “intellectual disability” and the roles and responsibilities they perceive for their intellectually challenged younger siblings. Data were obtained through semi-structured interviews from 5 participants including 5 adult siblings of 3 children with intellectual challenges. The adult siblings in the study reflected caregiving roles and supporting roles. They perceived that they have educational, parental and financial responsibilities toward their intellectually challenged siblings. The study also revealed the existence of conflicts among siblings due to the behavioural issues of intellectually challenged siblings, maternal attention, and the birth order. The study indicated a strong need for rising awareness among siblings of intellectually disabled children regarding the strategies to cope up with the existing siblings related issues in families of intellectually challenged children. The research also provides directions for future research in the area.

Keywords: Siblings Relationships; Intellectual Challenge

Article history:

Received on: June 07, 2022

Revised on: June 19, 2022

Accepted on: June 19, 2022

Published on: June 30, 2022

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INTRODUCTION

The siblings' relationship is the longest family-bond due to which it greatly affects development of all children in families.¹ The roles and responsibilities of siblings constantly adapt and change with the passage of time.² According to the life span, approach siblings are the companions, partners and role models in childhood.³ In young adulthood, the daily contact between siblings' decreases and peers become more important than siblings.⁴ Siblings tend to develop conflicts and rivalries in the period of adolescence but become a source of support in late adulthood specially when any brother or sister in family is less independent.⁵ Positive relationships which include warmth, support, companionship and affection among siblings lead towards positive life experiences and hold more value in development of children. Negative attitude of siblings characterized by aggression, conflicts, teasing, and rivalries on another hand can creates stress, anxiety and other psychological issues.⁶ Therefore, the core objective of this research was to explore the responsibilities and roles the adult siblings perceive for their younger intellectually challenged sibling. Children with intellectual challenges are those who have limitations in intellectual functioning and practical adaptive skills. Children with intellectual challenges require higher level of support and assistance from siblings than other normal children.

Living with a sibling with intellectual disability is often characterized with increased responsibilities and reduced parental attention towards normal siblings. Siblings of children tend to adopt caregiving responsibilities for their disabled sibling at very early age.⁷ In the variety of cases, they are more mature and have fewer conflicts. However, they develop conflicts and rivalries with the child with disability when they perceive that the parental attention is more inclined towards the child with disability.⁸

The adult siblings assume variety of roles and responsibilities towards the child with intellectual disability in the families. These roles are determined by the needs and circumstances of the family.

¹ M. Sommantico, S. Parrello, and B. De Rosa. "Adult siblings of people with and without intellectual and developmental disabilities: Sibling relationship attitudes and psychosocial outcomes." *Research in developmental disabilities* 99 (2020): 103594.

² Victor Cicirelli, *Sibling Relationships across the Life Span*, Springer Science & Business Media, 2013

³ Hilary E Travers, Mary Elizabeth Carlton, and Erik W. Carter. "Social connections among siblings with and without intellectual disability or autism." *Intellectual and Developmental Disabilities* 58, no. 1 (2020): 19-33.

⁴ Op.Cit., Sommantico, et al., 2020

⁵ Megan Gilligan et al. Multigenerational social support in the face of the COVID -19 pandemic, *Journal of Family Theory & Review* 12(12) , 2020 ,DOI:10.1111/jftr.12397

⁶ L.Marissa . Diener, & Groneman, A. Siblings with Disabilities. Book chapter in *The Encyclopedia of Child and Adolescent Development*, Eds S. Huppand J. , UK, John Wiley & Sons, In, 2019

⁷ Diener & Groneman, 2019

⁸ A. Zaidman-Zait, Yechezkiely, M., & Regev, D. The quality of the relationship between typically developing children and their siblings with and without intellectual disability: Insights from children's drawings. *Research in Developmental Disabilities*, 96, (2020), 103537.

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Few roles are willingly taken by the siblings to support their brother or sister with disability while others are directly assigned to them by parents and other family members.⁹ Adult siblings perceive themselves in the role of caregiver, friend, educator and role model for the special need siblings with varying levels of involvement. They are also the most important participant throughout educational process for children with disabilities since they share the same environment and some time the same school in case of inclusion. They serve as supporter and critical players for children with intellectual disabilities in interactive environments of community and school.¹⁰

Normal siblings of intellectually challenged children often have to compromise on their daily routine, and attending social events. They have to adjust their own lives according to the needs of the intellectually challenged children.¹¹ Therefore, the need for acceptance and awareness about the disability are the two core characteristics for siblings in developing positive perspectives towards the child with intellectual disability.¹²

In the context of Pakistan, the development of relationship quality for individuals with intellectual disability and their siblings has not been well addressed. Several pieces of research in the context of our country have addressed the issues faced by disabled children in acquisition of support services, problem faced by special children in school, special education curriculum, families and parents of children with disabilities e.tc. There is very little research done in Pakistan on adult sibling relationships, despite of the importance these relationships have in the life of children with intellectual challenges. Though the problems and the impact of disability on siblings were investigated but still a research gap exist in identifying the siblings' perspectives, their crucial part in both general and educational life a child with intellectual disability. Thus, in order to facilitate the positive relations, there is a need to understand intellectual disability from siblings' perspectives, siblings' experiences, their roles and their responsibilities. There is a strong need for research addressing how the unique combination of characteristics that define relationships for siblings of individuals with intellectual disabilities, specifically within the context of Pakistan. This research will be an attempt to explore the relationship of adult siblings with intellectually challenged child in their families, including their perceptions about intellectual disability, their roles and responsibilities in both general and educational life of an intellectually challenged child.

Awareness about siblings' relationship will provide the basis to develop teachers' understanding about child problems; it will give an insight to doctors, nurses, and paraprofessionals that they should involve the whole family rather than only parents when dealing with a challenged child. Psychologist and counselors can use this research as a foundation to counsel parents when they

⁹ Sarah A. Hall and Zachary Rossetti. "The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities." *Journal of Applied Research in Intellectual Disabilities* 31 (2018): 423–434.

¹⁰ Peggy A. Gallagher, , Julia H. Floyd, Alison M. Stafford, Teresa A. Taber, Susan A. Brozovic, and Paul A. Alberto. "Inclusion of students with moderate or severe disabilities in educational and community settings: Perspectives from parents and siblings." *Education and Training in Mental Retardation and Developmental Disabilities* (2000): 135-147.

¹¹ Pavlopoulou, Georgia, and Dagmara Dimitriou. "In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister." *Research in Developmental Disabilities* 97 (2020): 103556.

¹² Meghan M. Burke, Chung Eun Lee, Sarah R. Carlson, and Catherine K. Arnold. "Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities." *International Journal of Developmental Disabilities* 66, no. 1 (2020): 82-89.

are undergoing through stages of acceptance. Parents can directly benefit from the study, being more thoughtful about the relationships between their disabled and non-disabled children and by adopting strategies to cope with siblings' relationships problems. Policy makers, in addition, can develop more feasible and effective approach to deal with an issue of intellectual disability. The study also directs the attention of future researcher regarding this area.

Research Questions

- How do normal siblings perceive the term “intellectual disability”?
- What kind of relationships do normal adult siblings have with the intellectually challenged children in families?
- How do siblings recognize their roles and responsibilities in the life of intellectually challenged children?

LITERATURE REVIEW

Sibling relationship in any family is important and special since siblings are the first friends that one can have. Siblings help children to take first step towards social development and interaction with people other than parents. As a child grows, both negative and positive feelings cultivate towards their brothers and sisters. Every child has a different personality and temperament at different ages and their relationships are defined in accordance with these characteristics. Previous researches indicate that the characteristics in siblings of children with intellectual disabilities or any other disability are different as the disability of the sibling greatly influences the personality characteristics of non-disabled siblings. The prevalence of intellectual across the world has been estimated to be 1-3%.¹³The prevalence of intellectual disability in Pakistan is 17% with an estimated rate of 1.9% for severe intellectual disability.¹⁴

Researches highlights that with the passage of time, as parents grow older, the roles and responsibilities of caregiving special need shifts towards siblings. They become more responsible for the care of their intellectually challenged siblings or may face adjustment problems depending on the perceptions they have made towards their siblings.¹⁵ Thus, the siblings of children with intellectual disabilities have both benefits and disadvantages.¹⁶ The positive and negative nature of relationships between siblings can be affected by a variety of factors including the family's

¹³ Robert L. Sharon A. Borthwick-Duffy, Valerie J. Bradley, Wil HE Buntinx, David L. Coulter, Ellis M. Craig, Sharon C. Gomez et al. *Intellectual disability: Definition, classification, and systems of supports*. American Association on Intellectual and Developmental Disabilities. 444 North Capitol Street NW Suite 846, Washington, DC 20001, 2010.

¹⁴ Naureen Omar, and Farkhanda Kokab. "Intellectual disability among special children and its associated factors: A case control study, Lahore Pakistan." *JPMA. The Journal of the Pakistan Medical Association* 69, no. 5 (2019): 684-689.

¹⁵ Tamar Heller and Catherine Keiling Arnold. "Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning." *Journal of policy and practice in intellectual disabilities* 7, no. 1 (2010): 16-25.

¹⁶ Ibid. and

Gazi Begum, and Jan Blacher. "The siblings' relationship of adolescents with and without intellectual disabilities." *Research in Developmental disabilities* 32, no. 5 (2011): 1580-1588.

lifestyle, the family resources, their child-rearing practices, number of children, age differences between the children, the level of severity and the type of disability etc. It can be sometimes stressful and confusing for the normal child to accept the disabled child in the family, his response in return will affect the family as a whole.¹⁷

Stress also creates problems in the families as it affects the behavior of every family member. Some families are stressed by the number of financial resources required to meet the needs of the child who has a disability. The society and peers may create a feeling of humiliation or a sense of rejection in the nondisabled sibling because of their disabled sibling's physical condition or inappropriate behavior. All these reasons may create a sense of jealousy, resentment, and animosity towards their disabled brother or sister. The parents may fail to understand what their normal children are going through. At the other hand, it may also be difficult for the special need siblings to make others understand their needs. Most of the time they are left alone to play or not taken to social gatherings. They lack social skills and are unable to do things easily and quickly as their nondisabled brothers and sisters. All these things create a feeling of anger and frustration in them.¹⁸ Siblings may have no knowledge and awareness of the disability which also creates troubles in relationships. McKeever concluded from his study that siblings are least informed about the problems and the disabilities of their brother or sister. Yet they have a right and a need for information about it.¹⁹ It is important for them to understand the situation to deal and tackle disability.²⁰ Throughout their lives, they need information in a manner that is appropriate to their age and parents should respect this quest.

METHODS

Relationship between siblings is a complex phenomenon and in-depth information is required for understanding these relationships. The positive and negative emotions associated with these relationships cannot be researched through experiments and observations. Therefore, the researcher utilized qualitative research design to investigate the research problem. The researcher used semi-structured interviews to obtain in-depth information of the participants and the trustworthiness for the collected was maintained through member checks. The transcripts of the interviews were shown to the participants and their initials were taken on the transcripts to indicate that the information added is reliable and unbiased.

Data Collection and Analysis

Data collection and analysis was done according to the methods prescribed by Merriam and Tisdell (2016). According to them, the first step is to organize the data so that it can be easy to create meaningful units out of it. Researcher then creates categories and themes for further interpretations

¹⁷ Thomas H. Powell and Peggy Ahrenhold Ogle, *Brothers & sisters--a special part of exceptional families*, Brookes Pub.Co.1985

¹⁸ Op.Cit., Blacher & Begum, 2011

¹⁹ Patricia McKeever, Siblings of chronically ill children: A literature review with implications for research and practice. *American Journal of Orthopsychiatry*, 53(2), 1983, 209–218. <https://doi.org/10.1111/j.1939-0025.1983.tb03366.x>

²⁰ Helen Featherstone, *A Difference In The Family, Life With A Disabled Child* Hardcover, NY, Basic Books C, 1980

and connections with literature. Thus, the researcher tracked the following pattern. In-depth unstructured interviews were taken to understand adult siblings’ relationships, perceptions about the disability, their roles and responsibilities in educational and general life. The research required detailed understanding of experiences which wasn’t possible with structured interviews. Interviews were conducted with five adult siblings (three girls and two boys) of intellectually challenged children from three families.

The interviews were transcribed and translated into the English language. The initial translations were produced by the researcher, later they were endorsed by a fellow researcher from Institute of Social Sciences, Pakistan and a secondary level English language teacher from Beacon House School. The researcher labeled the distinct concepts “open coding” and made “axial codes” by developing links and comparing them to the concepts. Open coding involves breaking down the concepts, categorizing them and labeling them according to their characteristics. After open coding these categories are assembled into new concepts and connections are established.²¹ The researcher used thematic analysis to develop themes. Eleven themes have been identified after intensive analysis and investigation.

Ethical Consideration

The participants were assured of anonymity and confidentiality of their answers. They were told about the research and they gave their verbal consent

RESULTS & FINDINGS

The following table presents the research questions, themes extracted in answering to the proposed questions and the frequencies associated with them.

Table 1: Table of Frequencies

S.No	Research Question	Themes	Frequency
1	How do siblings perceive the term “Intellectual Disability”	Lack of Awareness about the Disability	3
		Definition of Disability based on Sibling Experiences	5
		Denial	3
2	What kind of relationships do normal adult siblings have with the intellectually challenged children in families?	Positive Relationships	5
		Conflicts due to birth order	2
		Conflicts due to behavior issues	2
		Parental Roles	3
3	How do siblings recognize their roles and responsibilities in the life of intellectually challenged children?	Supporting Roles	5
		Protective Roles	5
		Educational Responsibilities	3
		Financial Responsibilities	2

²¹ Sharan B Merriam and Elizabeth J. Tisdell. *Qualitative research: A guide to design and implementation*. John Wiley & Sons, 2016.

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The following categories emerge in response to the first research question “How do siblings perceive the term “Intellectual Disability”.

Lack of Awareness about the Disability

The adult siblings were totally unaware of both the term “Intellectual disability”.

A brother reported

“Her problems are natural and she doesn’t have any diagnosis. I have never heard the term Down syndrome or Intellectual disability.”

Another second born brother said

“I have never heard anything like Mongol, Down Syndrome or intellectual disability”

When the researcher asked about the meanings of intellectual disability one sibling said

“Well, I am not confirm about that but I have heard this from many that intellectually disabled people have very high IQ levels”

A sister who has been working in special education setup since two years said

“Intellectual disability means she is a special child, intellectual disability is very challenging due to the speech problems”

The siblings were unable to define the term intellectual disabilities even those sisters who were working in special education setup. However, they had some distorted concepts which were based on own experiences with the disability.

A brother said,

“Mongolian child doesn't have a normal mindset, they consume high diet, some children have slow speaking and high listening abilities while others have high speaking and low listening abilities”

It was apparent that siblings were not being taught about the condition of the disabled child in the family. They were uninformed about what impact the disability can have in the future and what do professionals recommend for the disability

One of the brothers highlighted

“After our parents’ death, she will live with us in the way she is living right now. We don’t have any idea about future yet but we will get the idea with time.”

The siblings are dealing with the disability in the light of their own experiences and observations. They don’t know about the proper diagnostic terms but understands that the special needs to some extent. Thus the other category that emerged relating to the research question was

Definition of Disability based on Sibling Experiences

The siblings knew that there are some problems which makes their disabled siblings different from normal

A brother said

“The difference between normal and special is that they cannot do things which normal people can, this is the only difference”

“She has a slow picking power. She faces difficulty in processing and giving output whenever she tries to pick anything. Her output is slow and she also has difficulties with alphabets, she cannot pronounce alphabet “S” properly and substitutes it with “F” or “P” alphabet sounds”

A sister’s words were

“People with intellectual disabilities face many challenges because they cannot speak, read or write like us”

Siblings were also neglecting the issues which fall into the category of denial.

Denial

The siblings were neglecting the facts that were apparent indications of the condition.

It was reported by a brother

“She doesn’t look like Mongolian by face unless someone observes her very closely. 70% people cannot recognize her disability unless they are being told, however, some of her reactions like eating or shouting shows that she has some problem. People also say that she is similar to normal and she is not a rare case, she will get better.”

While a sister described

“He picks and understands thing slowly. Besides, her understanding everything is ok”

While exploring the second research question, the researcher revealed very positive, supporting and friendly relationships. Although, some conflicts were also identifiable

Positive Relationships

The researcher found out that the disabled siblings have very friendly relationships with non-disabled siblings in families. The sense of affection, love, and closeness was constantly reflected throughout the interview.

A brother reported

“I have a very jolly relation with her, I like everything about her specially how she is fond of eating food, her diet”

A brother associated the feeling of happiness with their sister. Eldest brother said;

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“We feel a lot of change in our house environment because of her presence; her presence is a loud indication of life when she is not there, silence remains at home”

A sibling expressed

“My relationship became stronger as we grew older. I can understand her more day by day”

Conflicts Due to Birth Order

The siblings also reported some conflicts and quarreling in their relationships due to the birth order.

“I like teasing her because she stole my place”

“meri goud chaini hai usnay”

A brother said

“I am the eldest one among three brothers. My younger brother is jealous of her because he cannot accept someone younger than him in the house; I am the eldest so I don't care about these things. I sometimes feel that the younger brother gets annoyed and irritates her.”

Conflicts Due to Behaviour Issues

Siblings expressed the emotions of irritability, annoyance and shame due to the behavioral issues of their disabled siblings.

“A brother reported that stubborn behavior of their sister makes them annoyed.

“I don't feel right when she listens but don't follow. This thing is present in everyone but she irritates me when I tell her not to do something.”

“When we try to stop her from things, she tends to do those things more often”

Case A has learned some behaviors which the brothers consider socially inappropriate. They explained media as the cause of socially unacceptable behaviors.

“There are few small things which she has learned are those are negative. Things which are being played on YouTube and she has learned. Rest there is no problem. Things like dance and other behavior issues”

They refused to tell the details of those unacceptable behavior patterns as they were related to sexuality. This opens a new area for future studies.

“These children have to face many things so do us. They are going face many cultural changes; this generation has more knowledge about the things. We need to be careful about what children should know and what should we keep hidden”

On one hand, they blamed media as responsible for the behaviors related to sexuality, they were worried about the stubborn behaviors while on the other hand, they were reinforcing the issues.

A sister told that use to get annoyed and care about what others think when she was young but as she grew up she has developed more acceptance

“I was embarrassed of his shouting behavior when I was in school but as I grew up I realized it was not that embarrassing”

The third research question was regarding the roles and responsibilities of adult siblings. The most emphasized were the parental roles, financial and educational responsibilities. Although protective and supportive roles were also indicated.

Parental Roles

Two of the brothers declared themselves as the parents. The way they were concerned about the education, finance, behaviors and the disability itself was the clear indicating of parental roles.

“Bakhtawar is like my daughter and I treat her like a daughter”

Similar words were reported by Case C’s sister

“I am treating her like a mother and sometimes a teacher”,

Supporting Roles

Adult siblings were willing to support their intellectually challenged sibling in every possible way, they were concerned about interest, abilities, and choices of the intellectually challenged sibling.

As expressed by a brother

“We support her financially and, in every way, we can. She will be allowed to do whatever she wants to do in life, whatever she chose to learn”

A sister expressed nurturance for the intellectually challenged sibling

“I assist her in bathing and other self-help activities”

Protective Roles

The feelings of brotherly protective nature also emerged out of the data. Brothers were found concerned that their sister should not display inappropriate behaviours in front of anyone. Moreover, they displayed that they are sensitive and protective for their sister.

“We have to protect children from exhibiting such behaviours. It is understandable if a child is a boy but she is a girl so we have to give her more protection.”

At the other stance, the same brother expressed

“My support will remain same. No one can say anything to her”

Educational Responsibility

The education according to the siblings has foremost importance. According to them educational activities can eradicate disabled siblings' behaviour issues and bring them close to normal children. They were hopeful for inclusion; however, they expressed some over expectations unrealistic views that can be due to the unawareness. The following quotations represent siblings' responsibility towards education.

“As far as her education is a concern, the first thing is that she should be sent to school with the punctuality which is not happening. She must be regularly sent to school and efforts must be made for normal schooling. She should be provided with an atmosphere which is not bad for her. She must be taught with children who are moving from Mongolian to normal because she doesn't have a severe disability. Education will divert her mind to one side; she will become normal from Mongolian with proper education. She can set an example of turning normal from Mongolians for others”

A sister reported

“I am teaching in a special school so that I can assist her like a special educator but she is not attending any school due to her leg injury. I will get her admitted as soon as she become healthy”

Financial Responsibilities

The most unfavourable thing which displayed, its impact on every area discovered during the study was lack of finance. The financial pressure appears to affect the whole family and siblings considered finance as their utmost important responsibility. It was very unfortunate that a 22 years old adult sibling cried like a child in front of the researcher expressing his inability to control things due to financial burden and his desires for his sister betterment.

“I will admit her to the best school when I have money. Schools which are best for special children, where they teach everything according to the child's interest like if someone likes tailoring, they teach them tailoring, they also make them complete their Matric. I have also seen the video of that school; I really like that school but we cannot afford it”

Another brother uttered

There is a test for Mongolian children, which can indicate the severity of the disability, it's expensive but we will try for that test, we will also hire a teacher for her better future. If there were no financial issues, she would have been in good condition.

Starting from the diagnosis to education and rehabilitation, the main reason behind the lacking was finance. Finance was an endless struggle that the brothers were going through.

Discussion

After examining the findings of the study, it can be said that the education, rehabilitation, diagnosis and the treatment can be managed by those who are financially strong. The families who have financial issues cannot even think about the diagnostic and rehabilitation serves. The worries for

bread and butter restrict their life to a very short spectrum. Awan, Bibi, and Chaudary indicated the similar problems. They explained the financial pressures, lack of social support and anxieties about upbringing families as the indicators of hopelessness among the families of mentally retarded children.²²

However, these unfortunate families and the siblings within the families still survive making positive relationships as their strength. The levels of warmth, love, and affection among siblings make them forget their problems. Disability is not considered as a burden when feelings of love and affection are strong. A contemporary study by McHale and Gamble supports the findings; according to them siblings tends to have more positive interactions with their disabled sibling. A high level of empathy leads to increase the sense of responsibility, increased tolerance and encouragement, which was apparent in the findings of this study.²³

The present study also revealed the existence of conflicts due to the behavioral issues, maternal attention, and the birth order. According to Crnic and Leconte, knowledge about the disability can help children and adult siblings to deal with the uncertainty, fear, embarrassment, and misunderstandings associated with disability. Professional must involve the siblings because they have an important influence on the life of a disabled child.²⁴ The same phenomena was reflected from the existing findings, according to which adult siblings were annoyed and irritated about the behavior issues but they were unconsciously reinforcing the same behavioral issues which were due to the lack of awareness.

The denial and the concept for the normalization have also been evident in the literature. The adult siblings in this study several times indicated the comparison of their intellectually challenged child in their family with normal children. They were not ready to accept the fact that their siblings are intellectually challenged and their disability will exist with throughout their lifespan. Powell and Ogle, state that parents force the nondisabled siblings to accept their disabled children as normal, take up the financial pressures and to cover up for their sibling disability which results in assuming more responsibilities than normal.²⁵

Siblings in this study disabled the caregiving roles and responsibilities including parental and supporting roles, educational, financial and even marital responsibilities. They also had stress and overburden of responsibilities at a very young age.

²² Erum Abid Awan, Farzana Bibi, and A. G. Chaudhry. "Relationship of depression, hopelessness and associated attitude among parents of mentally retarded children." *Pakistan Association of Anthropology, Islamabad, Pakistan* (2015): 723-726.

²³ S. M McHale & Gamble, W. C. Sibling relationships and adjustment of children with disabled brothers and sisters. *Journal of Children in Contemporary Society*, 19(3-4), (1987)131–158. https://doi.org/10.1300/J274v19n03_08 and also

Wendy C Gamble, and Susan M. McHale. "Coping with stress in sibling relationships: A comparison of children with disabled and nondisabled siblings." *Journal of Applied Developmental Psychology* 10, no. 3 (1989): 353-373.

²⁴ K. A Crnic and J. M. Leconte. "Understanding sibling needs and influences." *Families of handicapped children: Needs and supports across the life span* (1986): 75-98.

²⁵ Op.Cit. Powell, Peggy and Ogle

CONCLUSION & RECOMMENDATIONS

The study revealed both positive and negative experiences regarding adult relationships with intellectually challenged child in a family. The positive relationships include the feelings of love, affection, and empathy for siblings while negative experiences relate to the conflict that the adult siblings have due to the birth order and behaviour issues of the children with intellectual disabilities. Moreover, it was revealed that the siblings were unaware of the disability and the ways to cope up with the disability. Siblings reported lack of acceptance and they have self-constructed definitions according to their experiences. They were unaware of the fact that disability is a lifelong condition. Rather than knowledge about the coping strategies for behaviour problems, they had false hopes and dreams for normalization. They were unaware that regardless of their affection, empathetic feelings and financial struggles for the better future for their siblings, things can get worse, especially the behaviour issues.

Further, the roles of the siblings consist of both supportive and parental roles. Female sibling displayed the motherly figure for the intellectually challenged child while male siblings were concerned more about the financial needs. They were facing the burden of financial and educational responsibilities as well. They had hopes that better education can bring a massive change in their sisters' life which they cannot afford.

The research after doing the in-depth study of the adult siblings, strongly recommend the need for awareness. The educationist and professional must start including the sibling in the pertaining awareness programs about Down syndrome and all other disabilities.

There is a strong need for community-based rehabilitation programs which can be initiated by the students of special education departments Karachi, the teachers and every professional that is related to disability so that the families struggling with finance have support groups to cope up with their diagnostic problem. In addition, government and media must help to promote sibling awareness, interaction, support and guidance by providing opportunities for siblings to learn about their disabled sibling.

The need for information and understanding is not only the parent's responsibility, but it should also be addressed by professionals and other family members. In some countries, progressive clinics and hospitals have designed programs and Family Support Groups which include entire family and bring them together as a means of sharing information and communal support. It is important for educators to be sensitive to nondisabled siblings' feelings and needs. Educators can also play important role in creating a positive sibling relationship and providing them awareness.

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