

Original Article

## Stuttering As a Disability in Pakistan; Policies and Its Implementation

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### ABSTRACT

**Objective:** Stuttering is a disorder of speech fluency not only includes academic and social consequences but also has emotional/behavioral outcomes. Stuttering leads to negative emotions and feelings i.e., low confidence, frustration, shame, embarrassment, poor self-image, and negative social identity. The present study was aimed at incorporating the definition of disability in Pakistan policy and determining the position of stuttering in it.

**Materials and Methods:** The nature of the current study is qualitatively conducted on 10 Participants approached through convenient sampling and exploring their responses through Thematic analysis. Participants falling in this category were recruited into the study from SLPs, Lawyers, disability advocates, and CSPs as per inclusion criteria. Common masses were excluded from the study. A Self-Developed Questionnaire/structured interviews were conducted. Questions developed by the Lawshe method. The tool was validated through content validity by 10 "experts".

**Results:** Thematic analysis was done and the findings of the study indicated an individual's negative reaction towards association with any kind of disability and communication barriers are also the main source of not fitting disability as a definition. Results also showed that lack of assessment and screening tools are the main barrier, however, Visibility as per data in research publications also consider a barrier towards recognition of it.

**Conclusion:** The study has practical implications regarding stuttering as a Disability in Pakistan.

**Keywords:** Disability, Pakistan policy, Stammering, Stuttering.

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## INTRODUCTION

Speech disorders such as stuttering and stammering can cause speech to become incoherent and have irregular temporal patterns.<sup>1</sup> Stammering is characterized by incoherent repetitions, pauses, inappropriate vowel production, unintended breaks, spasms, and emotional swings while speaking resulting in serious complications in communication.<sup>2</sup> There is no specific age for stammering.<sup>3</sup>

It involves various genetic and environmental factors responsible for the occurrence of this specific disability. Besides this, psychological factor also plays a significant role in the emergence i.e., parental, educational, and socioeconomic circumstances, anxiety-producing situations, such as parental conflict, being uprooted from their homes, and being separated from their siblings. Social and emotional variables "appears to be critical to the beginning and persistence of stuttering."<sup>4</sup> One of the research studies empirically supported it as Children with anxiety disorders or those who are more likely to experience situations where they are evaluated by others, such as social anxiety, separation anxiety, or generalized anxiety disorder, may speak with dysfluency and panic. Displacement situations include all of these anxiety-provoking circumstances<sup>5</sup>.

To provide the legal framework to guarantee that individuals with disabilities have equal opportunity in all facets of life. A survey conducted by Pakistan Census Organization (PCO) gathered information on disability in seven categories during its 1998 national population census: Crippled Insane; Mentally Retarded; Multiple Disability, Blind; Deaf, Mute; and Others. According to Census data, 2.49 percent of the population was made up of people with disabilities. Punjab has the highest percentage of disabled people (55.7%), followed by Sindh (28.1%), NWFP (11.1%), Baluchistan (4.5%), and Islamabad (0.3%). A physical disability characterizes the majority of those with

disabilities, followed by hearing loss<sup>6</sup>.

But still, this data lacks because not all special people were included in these numbers. So in turn there is still no proper management for dealing with individuals with such disabilities. Although these citizens, even if they work, cannot afford to pay full ferry fare in Pakistan, the Superior Residents (Right to Movement Concessions) Act, which remained passed in 2009, aims to afford special persons with concessionary rates in all modes of public and private transportation, but its results have not been fully examined.

Numerous studies have empirically proved this lacking and explained its serious consequences. As one of the studies reports Persons who have been obligatory or indulged to leave their family unit or places of characteristic residence, in particular as an outcome of or in command to avoid the special effects of armed conflict, conditions of global violence, violations of human rights, or expected or human-made misadventures, and who have not intersected any international borders.<sup>7</sup> According to one idea, it's unclear how race, ethnicity, culture, bilingualism, and socioeconomic level affect the frequency and prevalence of stuttering.<sup>8</sup> Everyone has the right to fundamental freedoms including fair and equal treatment. Education, work, and the right to dignity are essential and should be available to everyone.<sup>9</sup>

Sadly, it is likely that underprivileged people do not have access to these rights. Such a vulnerable population includes those with impairments. The degree to which the societal structure and support system adequately meet the requirements of everyone determines how functional people with disabilities are in society. Persons with disabilities comprise those who have an enduring bodily, mental, rational, or sensual impairment that could preclude them from fully and effectively participating in culture on an identical center with others, permitting the UN Convention on the Privileges of People with

Infirmities.<sup>10</sup>

Due to terrorism and counterterrorism efforts, Pakistan has a sizable internally displaced population, which may have contributed to an increase in emotional, psychological, and communication difficulties such as speech disorders, particularly stammering. The researcher is aware of no investigation on this significant health issue from this region of the world. Therefore, the goal of the current study was to establish stuttering as a handicap under Pakistani law. This study is crucial since there are so many stutterers in the world, no matter where they live.<sup>11</sup>

If we dig deep into the causes of stuttering, we have come to know about the various concepts about the reasons. Some include any stuttering history in the family, family dynamics, neurophysiology, and childhood development. Neurogenic stuttering may result from brain damage following a stroke. Psychogenic stuttering may result from severe emotional trauma. A hereditary defect in the area of the brain that controls language may explain why stuttering runs in families. Your children may stutter if you or your parents did. The ability to speak fluently can be hampered by factors other than developmental stuttering. Sluggish speech, including pauses or repeated sounds, might be brought on by a stroke, traumatic brain injury, or other brain problems (neurogenic stuttering). Speech fluency can be affected by emotional strain as well. Dysfluency can occur in speakers who do not stammer when they are anxious or under pressure. Additionally, these circumstances might make stuttering speakers less fluent. Psychogenic stuttering is a rare form of speech impediment that differs from developmental stuttering in that it manifests after emotional stress.

"Disability" is defined in the Pakistani context in terms of someone who is handicapped for responsible for any productive occupation or employment in command to earn a living" in

Pakistan. This definition includes people who are blind, deaf, physically challenged, or mentally retarded.<sup>12</sup> Moreover, It has different types including Speech (A disability involving stuttering, incorrect articulation, and speech), Language disorder (Difficulty in expressing thoughts, ideas, and feelings or comprehending), Traumatic Brain Injury (Any open or closed head injury caused by an external force, such as an accident, being struck by an object, or another head injury that significantly affects the brain), blindness and visual Impairment (A person is deemed visually impaired if they still have a vision issue even after using glasses or other corrective devices), Hearing Impairment (A hearing impairment, either eternal or variable, that has an adverse effect on a kid's academic achievement).<sup>13</sup>

One of the significant aspects of the present study is to discuss the Disability policies of Pakistan over the years. The analysis of data in this context has examined the following policies that had been formulated in this context. The government of Pakistan has enacted several laws to enhance the lives of people with disabilities, including the "Disabled Persons (Employment and Rehabilitation) Ordinance 1981" and the "Literacy Ordinance 1985," which was approved by Parliament in 1987.<sup>14</sup> The policy was updated in 1988 to more effectively and efficiently meet the requirements of those with special needs. Even though the 1999 special education policy was designed to address the issues facing this underprivileged group in society.

The Pakistani government unveiled a national policy on the subject of disabilities in late 2002, as well as a "National Plan of Action in 2006 for Persons with Disabilities" was unveiled the following year. To grant special status to extraordinary people, the "Special Citizens Act, of 2008" was later passed. A year later, the "Exceptional Citizens (Right to Movement Concessions) Act, 2009" existed announced to assist special individuals, particularly special students.<sup>15</sup> The Pakistan National Education Policy

2017 emphasized the need to provide the greatest number of facilities to give everyone access to equitable educational opportunities. In this sense, the government must create a welcoming environment for learning where all kids have an equal chance to interact and learn together.<sup>16</sup> Children with disabilities are more at risk in underdeveloped nations like Pakistan than they are in the industrialized world. Such children in Pakistan have two issues: first, they are disabled, and second, they are from underdeveloped countries, which makes them more vulnerable in many areas of life.<sup>17</sup>

Furthermore, talking in terms of Main streaming Disability Interventions in the National Youth Action Agenda of Pakistan, we have come to know that there is a lot more improvement in addressing the issues of accessibility, associated poverty, and youth opportunities. The policymakers are more concerned with ensuring that the national youth policy must include all the significant components of disability policies. WHO is also collaborating on many projects to work on these significant issues and eradicate the issues in our context. World Health Organization's representative for Pakistan emphasized the importance of national policies that offer youth with disabilities equal opportunity, inclusion, and economic prosperity. The WHO's leadership and thorough help in creating disability legislation, a strategic action plan for disability, improving access to assistive technology, and improving disability data are valued by the Government of Pakistan. The Planning Commission's efforts were applauded by the Parliamentary Secretary for Health, who emphasized that for inclusive growth, all budgets, policies, and programs must be developed with the population of people with disabilities in mind. Additionally, she emphasized the importance of disability<sup>18</sup> censuses, institutional access, education, skill development, and employment prospects. All human beings have the right to all such basic requirements that enable them to live happy and prosperous lives,

regardless of gender, religion, caste, class, ethnicity, or disability. However, in Pakistan, children with disabilities are denied the rights that ensure their security and success in a variety of areas of life.<sup>19</sup> These limitations include a lack of access to possibilities for money, recreation, health benefits, and education.<sup>20</sup> Cites the UNESCO estimate, for instance, that 99 percent of girls in poor nations are fully illiterate and 98 percent of male children with impairments are not in school.<sup>21</sup> Children with disabilities in Pakistan struggle to integrate into society and suffer a variety of issues, including a lack of funding, medical resources, and employees that are qualified to meet their requirements.<sup>22</sup>

In Pakistan, there is little research on disability and little work has been done to treat stuttering as speech impairment. Due to the perceived lack of research on the topic, this study has been undertaken to gain the most comprehensive understanding of it and to choose the best course of action to address its drawbacks. So the present study has significant implications in the context of developing and improving policies for disability.

This study will help explore the position of stuttering in the Pakistani disability service provision context as well as the definition of the disability. A probable case for its inclusion in terms of either a disability or a difference can be proposed opening areas of accommodation or modification for people who stutter.

## **MATERIALS & METHODS**

### **Study Design & Setting**

The study design used for this literature was Qualitative research. The study was conducted inside Rawalpindi/Islamabad for six months after the approval of the synopsis. A total of 10 participants were included.

### **Sampling Technique**

A convenient sampling technique was used.

## SAMPLE SELECTION

### Inclusion Criteria

Participants falling in this category were recruited into the study from SLPs (Speech and language pathologists), Lawyers, disability advocates, and CSPs (Civil Service of Pakistan).

### Exclusion Criteria

Common masses were excluded from the study.

### Data Collection Tools

A Self-Developed Questionnaire/structured interviews were conducted.

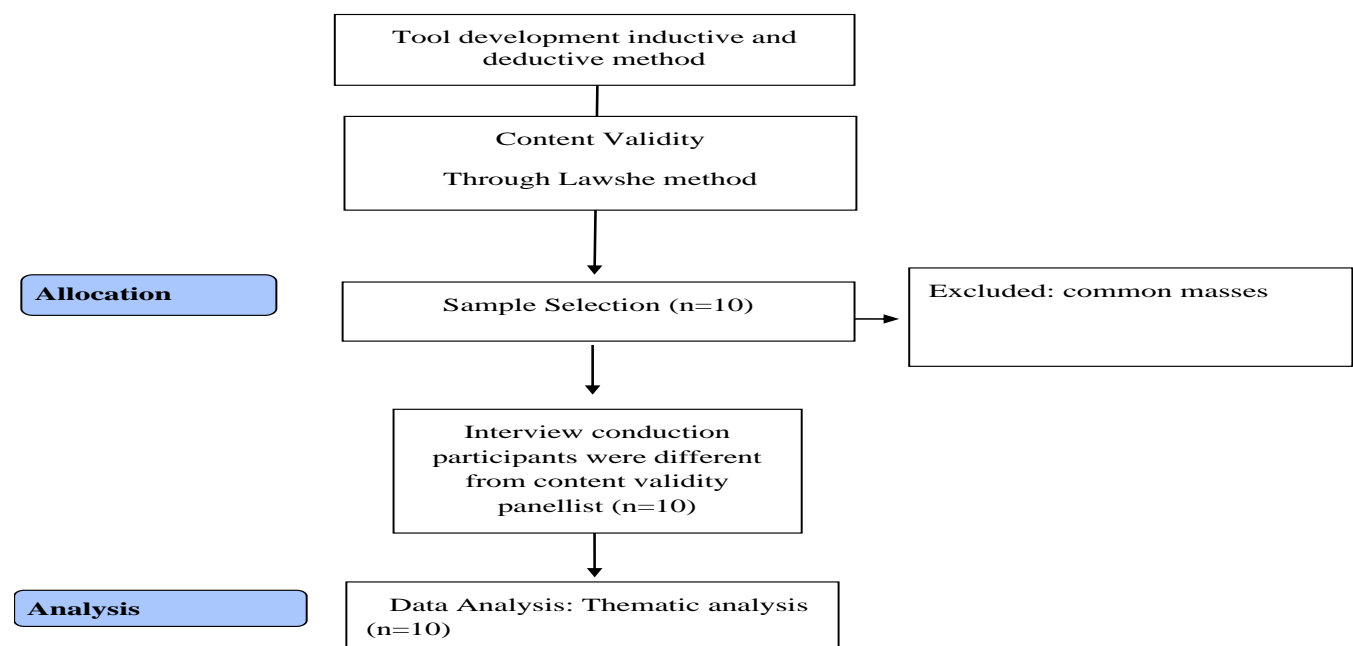
Content validity involves the evaluation of a new survey instrument to ensure that it includes all the items that are essential and not essential items to a construct domain.<sup>37</sup> The judgmental approach to establish content validity involves literature reviews and then follow-ups with the evaluation by expert judges or panels.

Content validity following these steps:

- An exhaustive literature review was done on the connected objects.
- A poll on content validity was created, and each item is graded on a three-point scale (not necessary, useful but not essential, and essential).
- The survey was distributed to subject-matter experts in the study's area of study.
- A Content Accuracy Ratio (CVR) was then calculated for each item using the Lawsche (1975) method.
- Items that are not significant at the critical stage were excluded.

### Data Collection Procedure

In PHASE 1 of the study, the tool was validated through content validity. In PHASE 2 of the study, a questionnaire had been formally designed, the researcher conducted interviews with participants.



**Figure 2.1: Flow Diagram**

## Data Analysis Procedure

The data analysis of the study was through thematic analysis; Thematic analysis is a method for analyzing qualitative data that involves reading through a set of data and looking for patterns in the meaning of the data to find themes.

## RESULTS

### Gender Distribution

There were 4 men and 6 women.

### Subjects/Participants

This study was conducted to determine the position of stuttering and the definition of disability in Pakistani policy. 10 experts participated from different relevant fields SLPs, Lawyers, disability advocates, and CSPs as per inclusion criteria. Questions developed by the Lawshe method which is a linear transformation

of a proportional level of agreement. The tool was validated through content validity. Total of 10 experts within a panel rate an item as essential. The least acceptable value for 10 expert panels is 0.75. The researcher conducted interviews with participants. Data were analyzed through the thematic analysis of all the variables. The given tables show a descriptive analysis of results with other variables in detail.

Table 1 shows the content validity of questions developed by the Lawshe method which is a linear transformation of a proportional level of agreement, Total 10 "Within the Panel Rate an item Essential in the corresponding way  $CVR = (ne N/2)/N/2$ .

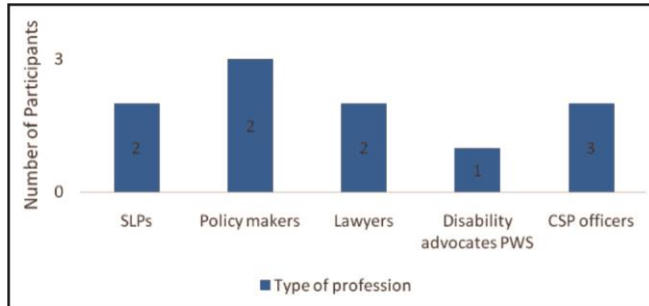
The least acceptable value for 10 expert panels is 0.75

Figure 1 shows the frequency of the type of profession, in which 2 were SLPs, 2 were Lawyers, 2 was disability advocate, 2 were Policy makers and 2 were CSPs.

**Table 1:** Content Validity Ratio.

Item No.	Number of participants										Ne	CVR Relevance
	1	2	3	4	5	6	7	8	9	10		
<b>Q1:</b> What is the definition of disability in Pakistan?	4	4	2	4	4	4	3	4	4	4	0.9	0.8
<b>Q2:</b> Why stuttering does not fit in the definition of disability in Pakistan?	4	4	4	4	4	4	4	4	4	4	1	0.8
<b>Q3:</b> What can the legal/Policy/bureaucratic fraternity do to include it in the disability act?	4	4	4	3	4	4	4	4	4	4	1	1
<b>Q4:</b> How is a newly recognized disability added to the NADRA disability list?	4	4	4	4	4	4	3	3	4	4	1	1
<b>Q5:</b> What procedures should be in place to determine the severity of stuttering?	4	4	4	4	4	4	3	3	4	4	1	0.8
<b>Q6:</b> What are the barriers to recognition of a speech-based disability?	4	4	4	4	4	4	3	3	4	4	1	1
<b>Q7:</b> What are the kinds of benefits that should be made available to a person who stutters?	4	4	4	4	4	4	3	1	4	4	0.9	1





**Figure 1:** Types of Profession.

SLP: Speech-language Pathology, PWS: Person with Disabilities, & CSP: Civil Service of Pakistan

Table 2 shows the frequency of years of experience of the participant in which 8 participants had an experience of 5 – 10 years, 1 participant had an experience of 10 – 15 years and 1 participant had an experience of more than 15 years.

Table 3 shows that the majority of the participants (n = 5) responded that disability is

something that possess a hurdle inability to perform the daily activity of living, while some of them (n = 4) said it is something that possess hurdle in employment, 2 participants (n = 2) responded it is something that compromises in mental health and physical disturbance, however, 1 participant (n = 1) describe it as discrimination against PWS, something that possesses hurdle in educational progress and as well as social adjustment or movement.

Table 4 represents that (n = 4) participants responded in their interview that compromised health-seeking behavior is the main source due to which it does not fit in the definition of disability, (n = 3) participants talk about the negative reaction towards association with any disability, and the communication barriers, however (n = 1) interviewed that due to the hindrance in job or workplace is the reason.

**Table 2:** Years of experience of the participant

Years of Experience	1 – 5 Years	5 – 10 Years	10 – 15 Years	More Than 15 Years
Number of participants	0	8	1	1

**Table 3:** Q1: What is the definition of disability in Pakistan?

Theme	No. of Participants
Something that possess a hurdle in the ability to perform daily activity	5
Something that possesses a hurdle to employment	4
A compromise in mental health	2
Physical disturbance	2
Something that possess a hurdle in educational progress	1
Social adjustment/movement	1

Table 5 shows that the majority of the participant (n = 8) thought a legal framework for making laws/policies and action plans should be

made for disabled persons, some of them (n = 6) responded on rightful employment is being neglected, according to 3 participants (n = 3) there should be an implementation in inter-sectoral and inter-departmental level and the meanwhile (n = 1) participant responded as society's attitude towards disabled people.

**Table 4:** Q2: Why stuttering does not fit in the definition of disability in Pakistan?

Theme	No. of Participants
Compromised health-seeking behavior	4
The negative reaction towards association with any disability	3
Communication barriers	3
Representation incenses	1

**Table 5: Q3:** What can the legal/Policy/bureaucratic fraternity do to include it in the disability act?

Theme	No. of Participants
An action plan should be made	8
Legal framework for making law/ policies	8
Right employment is being neglected	6
Political execution of legal policies	6
Implementation is an inter-sectoral and inter-departmental activity	3
Society's attitude toward disabled people	1

Table 6 shows that the majority of the participants (n = 7) were not sure about the answer that how newly recognized disability was added to the NADRA disability list, however (n = 2) participants talk about Supreme courts/ ministerial/legislative recommendations.

**Table 6: Q4:** How is a newly recognized disability added to the NADRA disability list?

Theme	No. of Participants
Not sure about the answer	7
Supreme courts/ministerial/legislative recommendations	2
publication in the official gazette	1

Table 7 shows the frequency of procedures that should be in place to determine the severity rating scale/instrument used to check (n = 7) however some of the participants (n = 6) suggested a disability classification model to determine the level of severity.

Table 8 shows that (n = 4) participants interviewed about lack of assessment and screening tools as a main barrier, however (n = 3) participants reported Visibility in research data country-wide census and stigmatization on the way of speaking are the barriers, (n = 2) said that political will to consider stuttering as a disability.

Table 9 shows the kinds of benefits that

**Table 7: Q5:** What procedures should be in place to determine the severity of stuttering?

Theme	No. of Participants
Severity rating scale/instrument used to check	7
Disability classification model (mild, moderate, and severe) used to identify the severity of disability	6

**Table 8:Q6:** What are the barriers to recognition of a speech-based disability?

Theme	No. of Participants
Lack of assessment and screening tools	4
Visibility in research data country-wide census	3
Other important problems take precedence over stuttering	3
Stigmatization on the way of speaking	3
Lack of visibility/ economic activity participation	2
Political willingness to consider stuttering as a disability	2
Poor health-seeking behavior	1

**Table 9: Q7:** What are the kinds of benefits that should be made available to a person who stutters?

Theme	No. of Participants
Special quota providence for stuttered person	9
Speech therapy sessions	3
Accommodation in various services for example job interview facility to write	3
Early interventions should be performed at the school and community level.	2
Good community behavior towards the stuttered person	2

should be made available to a person who stutters (n = 9) majority of the participants reported special quotas providence for the stuttered person, (n = 3) participants interviewed speech therapy sessions should provide to all stuttered persons and give some accommodation



in various services for example in job interview facility to write, (n = 2) participants indicated towards good community behavior towards the stuttered person.

## DISCUSSION

To determine the definition of disability participants revealed that the disability is something that possesses a hurdle in the ability to perform the daily activity of living, the majority of participants consider disability that possesses a hurdle in employment, and (n = 2) participants think disability that possesses a hurdle in educational progress. The previous study entails disability is typically described as the inability or difficulty of performing fundamental daily tasks or other activities that are necessary for an independent life without help. Disability has no obvious boundaries, and it can be challenging to define different levels in different patients, especially when talking about functional disability.<sup>24</sup> Another study describes disability as a multifaceted phenomenon. According to one example, disability is a multifactorial condition including physical and mental health. To account for the complex and individualized phenotype better of disability, previous study's data are used to update the International Classification of Functioning, Disability, and Health Adaptation of the World Health Organization for disability. They are also used to create the definition of stuttering experiences as a disability based not simply on listeners' interpretation but also lying on the impact of disability on the life of adults who stammer.<sup>25</sup>

The majority of participants (n = 5) consider compromised health-seeking behavior as the main reason why stuttering doesn't fit in the definition of disability in Pakistan and few participants (n = 4) reveal that an individual's negative reaction towards association with any kind of disability and communication barriers are also the main source of not fitting it in a

definition of disability. Similarly, findings were noted in a study that many other countries do not consider stuttering as a disability. However, stuttering does fit in the American classification of disability and they considered it as a disability in 1998 they added in their laws and policies.<sup>26</sup>

The majority of participants (n = 7) illustrated that they are not sure about the answer that how newly recognized disability was added to the NADRA disability list, and few (n = 2) participants (n = 2) think legislative order and ministries decisions can put it in the NADRA disability list. As such no specific literature is available on the NADRA disability list. However, it was observed according to a case study of Pakistan, that people with disabilities are being neglected and laws by policymakers are not being implemented. Also, it is noted that laws and policies based on disabled preferences undermine the principle and objectives of the same citizenship. In light of the international human rights standards, the national legislation must thus reflect international commitments' observance.<sup>27</sup>

The study also reveals that the majority of participants (n = 3) consider political willingness as a barrier towards recognition of stuttering as a disability, few participants think that lack of assessment and screening tools is also the main barrier, however, Visibility as per data in research publication also consider barrier towards recognition of it. Similarly, the study concluded that people stuttering experienced limitations in participation because they stutter; there are consequences for their future ability to remain independent and connect with relevant people and services.<sup>23</sup> Another study gathered perceptions of the barriers to work integration from different types of stuttered people from service providers and employers. This concluded that many barriers be common crosswise types of stutter disability. Although some common barriers were identified as communication barriers and stigmatization. People generated an equally long list of barriers but were very worried

about the job market issue also.<sup>25</sup>

The study also concluded that the majority of participants suggested that special quotas providence for PWS should be announced and few participants (n = 3) think that some accommodation should be provided for stutters in various services for example in job interview facilities, and few participants also reveal that Speech therapy services should be considering must. In contrast, previous researchers found that Adults utilizing an impairment-based approach to stuttering treatment that just addresses speech behaviors is not comprehensive and does not adequately address the range of covert elements associated with the disorder, such as avoidance and internalized thoughts and feelings. Therefore, it is advised that stuttering intervention be approached holistically. The goal of another study was to determine the level of web-based information that Australian public institutions and their related disability association services provide for present or potential stuttering students. The findings show that there is a lack of resources for stuttering students or potential students on Australian university websites. Only 13% of the websites acknowledged using alternative teaching and assessment methods for children who have speech impairments<sup>28</sup>

## CONCLUSION

This study determined the definition of disability as something that possesses a hurdle in the ability to perform the daily activity of living, possess a hurdle in employment, a compromise in mental health and physical disturbance, possess a hurdle in educational progress, and as well as social adjustment or movement. However, stuttering is not considered a disability under Pakistani policies. There should be accommodation and implementation of laws in Pakistani policies for disabled persons.

## Limitation of study

Saturation was not achieved in question number 4. Diversity in the sample size was required for that question.

## Recommendations

People with stuttering having a position of power should have been recruited.

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## Additional Information

**Disclosures:** Authors report no conflict of interest.

**Ethical Review Board Approval:** The study was conformed to the ethical review board requirements.

**Human Subjects:** Consent was obtained by all patients/participants in this study.

**Conflicts of Interest:**

In compliance with the ICMJE uniform disclosure form, all authors declare the following:

**Financial Relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work.

**Other Relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

**Financial Relationships:** None.

## AUTHORS CONTRIBUTIONS

Sr.#	Author's Full Name	Intellectual Contribution to Paper in Terms of:
1.	Aqsa Malik	1. Study design and methodology.
2.	Romana Pervez	2. Paper writing.
3.	Gul Nayab	3. Data collection and calculations.
4.	Nusrat Naseem	4. Analysis of data and interpretation of results.
5.	Zaish Awan	5. Literature review and referencing.
6.	Aqeel Ahmed	6. Editing and quality insurer.
7.	Shoukat Hayat	7. Final review.
8.	Muhammad Ibrar	8. Analysis of data.