Perceived Family and Organisational Support among People with Dwarfism in Tamil Nadu, India: A Qualitative Inquiry

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ABSTRACT

Purpose: *Despite the fact that society has slowly become more inclusive of those who are viewed as different, people with dwarfism still experience discrimination in every aspect of life. This study aims to understand their perceptions about family and organisational support in combatting the day-to-day challenges they encounter.*

Method: *Face-to-face in-depth interviews using a semi-structured interview guide were conducted with twelve adults with dwarfism. The selected participants were those currently living with their families and with membership in the Tamil Nadu Dwarfism Welfare Association, an NGO, for at least two years. The gathered data was analysed manually using the thematic analysis technique.*

Results: *The major themes that evolved were infrastructural modification, emotional support, access to education, career guidance and partner selection. Each theme had sub-themes which were examined through the lens of both family and organisational support.*

Conclusion: *Support from family can be constructive as well as destructive, often on the basis of the socio-economic status of the immediate family members. On the other hand, support from welfare organisations for the empowerment of people with dwarfism is in general positive. However, the findings from this study cannot be generalised to all people with dwarfism as the study focused solely on the perspectives of members of an organisation, and there were many people who were reluctant to participate in the in-depth interviews.*

Key words: *people with dwarfism, people of short stature, family support, organisational support*

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INTRODUCTION

Dwarfism is a medical condition, with a characteristic of unusually short height of about 147 centimetres or less, caused by changes in bone and cartilage growth (Little People of America, 2020). In India, the Rights of Persons with Disabilities Act was amended in 2016, raising the number of disabilities from 7 to 21, that included dwarfism as one form of physical disability. In spite of this amendment, dwarfism is recognised as just a physical difference in body size rather than a disability, and the accompanying medical conditions are not always apparent (Thompson et al, 2008). Experts in the field of disability studies argue that no other collective identity with respect to impairment has been shaped predominantly by cultural representation (Pritchard & Kruse, 2020). The roots of this misrepresentation can be traced back to the stereotypical portrayal of people with dwarfism in popular culture, especially in art, literature and media (Barnes, 1991; Pritchard & Kruse, 2020). For years they have been considered to be less human and less worthy of respect (Garland & Thompson, 2009) as they are often associated with entertainment. In circuses they are encouraged to perform the role of clowns, and when it comes to modern cinema, they are hired to act as comedians. These representations have shaped, and continue to shape, the perceptions of society by laying emphasis on their appearance rather than talent. Such prejudices have created conceptual tension and forced people with dwarfism to remain among the vulnerable groups, struggling to make ends meet.

Day-to-day Challenges

The social complexities of dwarfism are perceived differently from other forms of physical disability (Ablon, 1990) as they do not possess any cultural markers of disablement to indicate functional limitations, like a wheelchair or any additional forms of assistive devices (Pritchard, 2014). However, in reality, it is observed that the differences in their body structure, including shorter limbs, shorter fingers and bowed legs, have resulted in infrastructural barriers to accessing public spaces and amenities. Since the built environment is constructed for an average-sized person, the mismatch in their height has an impact on how they interact with the social space (Pritchard, 2020). Their accessibility issues begin at home, where many aspects of a standard house, such as shelves, switchboards, countertops, doorknobs, etc., are designed for an individual of average height (Baidi et al, 2018). In the case of public places, accessing public amenities like restrooms, ATMs, shopping complexes, and restaurants become tedious. The absence of appropriate seating arrangements in the employment, educational and healthcare sectors is one of their major concerns. Above all, transportation is a persistent obstacle, making daily commutes challenging. To resolve such infrastructural barriers, it is significant to recognise people with disabilities, not as a homogeneous group but as a group made up of various impairments with diversity (Shakespeare, 2006). This perspective will certainly aid in considering the needs of people with dwarfism before implementing suitable infrastructural facilities for the physically challenged in public spaces (Pritchard, 2016). Furthermore, they experience psycho-social challenges on a daily basis, that consequently lower their mental well-being (Kathryn & Alan, 2020). They are categorised as physically unfit to perform certain roles and are labelled as people with a difference. Humiliating names, unsolicited comments and derogatory phrases are used on them, owing to the difference in their bodily features. People with dwarfism are stared at in public and are often subjected to unauthorised picture-taking (Ellis, 2018). As a result of all this, fear of being negatively judged is implanted in their minds and restricts their engagement in social situations. In order to combat the aforementioned challenges and become resilient, support from the family and the organisation becomes vital.

Operationalisation

Family support is conceived as an informal means of assistance provided to people with dwarfism by their immediate family, including parents, siblings, spouse and children.

Organisational support refers to formal support received by people with dwarfism from the welfare association functioning exclusively for people with dwarfism.

Need for Family and Organisational Support

For people with dwarfism, one of the available resources to promote adaptation is the support received from both the informal and formal institutions, namely the family and the organisation.

Family is the intrinsic social institution which is pertinent to fulfil the needs of people with dwarfism by providing a wide range of assistance to them (Grossman et al, 2016). Family support begins with acceptance, the most influential element in providing support to combat their environmental challenges (Lara et al, 2017). The emotional support obtained from family helps to reduce their psychological distress (Benka, 2012) and promotes a sense of belongingness. People with dwarfism possess innate potential necessary to successfully navigate life (Onalu & Nwafor, 2021) and the family strengthens this by inculcating a set of life and social skills to enhance their social competence.

In addition, people with dwarfism experience problems with their self-esteem and body image that arise due to stigmatisation and social expectations (Silva et al, 2017). In this regard support from organisations functioning exclusively for people with dwarfism promotes a certain philosophy on how to live with the existing conditions (Pritchard, 2021). It also aids them in voicing their own opinions, determining their needs, expressing views and standpoints on priorities, assessing services, advocating change and public awareness. It encourages them to form secondary social relationships and enlarge their support networks, especially with those who share similar experiences.

Therefore, for a person with dwarfism to successfully navigate the existing social system, support from the family and organisations is indispensable.

Objective

The existing literature on people with dwarfism focussed only on the issues of stereotyping, cultural depiction and media portrayal. The denial of not belonging to the category of traditional handicaps (Thompson et al, 2008) failed to lay emphasis on the support mechanisms necessary to combat their challenges. Hence, this study is framed to understand the perceptions of people with dwarfism regarding the support received from family and organisations.

METHOD

Study Setting

Tamil Nadu is a South Indian state, with Chennai as its capital city. The Tamil Nadu Dwarfism Welfare Association, located in Chennai, is the only non-governmental organisation functioning exclusively for the empowerment and welfare of people with dwarfism in the state. This organisation has around 60 individuals with dwarfism as its members, from both rural and urban backgrounds, representing different parts of the state. They work closely with the government agencies to promote their accessibility, especially in the educational, employment and healthcare sectors.

Study Participants

Purposive sampling technique was used to select 12 participants, in the age group of 20-40 years, from the aforementioned non-governmental organisation, emphasising equal representation of men and women. This technique has the flexibility of targeting the participants who are expected to provide rich and in-depth information related to the research questions.

Inclusion criteria of the study:

Participants who were those currently living with their family (to elicit their perceptions about family support), with at least two years of membership experience with the non-governmental organisation (to understand their perceptions on organisational support). In order to represent the study participants, the researcher has used the terms 'people with dwarfism' and 'people of short stature' alternately.

Data Collection

Constructivist approach takes an epistemological stand, in which knowledge is regarded to be constructed (Gerstenmaier & Mandl, 2001). This approach views reality from the perspective of the study participants. Individual face-to-face in-depth interviews were carried out by the first author for about 45-60 minutes to gather information on the research objectives. The researcher introduced herself and her affiliation with the university and assured participants that the study was only for the purpose of enriching scientific evidence through academic writing. Participants were made aware of the aims and method of the study and were offered the freedom to leave the study at any time. Permission to record the interview and written informed consent forms were obtained from all the participants and their data confidentiality was guaranteed. Interviews were initiated with the set of open-ended questions, followed by probing questions on the basis of their response. A few of the sample open-ended questions as indicated in the guide are given below:

- Can you tell us about your family and in what ways they were supportive?
- How does your family help you to cope in times of distress?
- What kind of informational support do you receive from the organisation?
- What role does the organisation play in empowering your personal life?

Data Analysis

Data analysis was done manually by the researchers. The audio recordings were transcribed verbatim and translated to get a deeper understanding. Thematic analysis (Braun & Clarke, 2006) was carried out, wherein the researchers read the transcripts multiple times for familiarize with the available data and then started to generate initial codes manually. After the completion of initial coding, an overarching category was derived by clubbing similar meaningful codes. The codebook had labels or tags assigned to the segments of data that captured meaningful concepts or ideas. The summarised data was aggregated for interpretation and systematically grouped in categories to form themes. The researchers discussed and further revised the themes during subsequent meetings until the final themes were established.

Ethical Considerations

Permission to conduct the study was received from the research supervisor and the lead researcher's doctoral committee members had a thorough scrutiny of the study design, semi-structured interview guide and study procedures.

RESULTS

Socio-demographic Profile

The socio-demographic profile of the respondents is summarised in Table 1. Equal representation was given to both male and female participants, with a majority (67%) belonging to the age group of 30-40 years. Half of the respondents (50%) had education below secondary school level; the study found evidence of dropout rates. Despite all the participants being in the working-age category, only 7 of them were employed. This is due to the misconception that people with dwarfism are incapable of completing a task and lack productivity. Half of the respondents were married; one respondent had a spouse with dwarfism while the remaining five were married to persons with other forms of physical disability. This proves that the average height person is generally not interested in marrying a person with dwarfism. The widow who participated in the study had lost her husband due to HIV. Four participants had one child each; among them, two of the children were born with dwarfism.

Table 1: Socio-demographic Profile of the Respondents

Characteristics	Category	No. of Respondents	Percentage
Age (years)	20-30	4	33
	30-40	8	67
Education	Below Secondary	6	50
	Up to Higher Secondary	2	17
	Under graduation	4	33
Employment Status	Unemployed	5	42
	Employed	7	58
Marital Status	Married	6	50
	Unmarried	5	42
	Widow	1	08
No. of Children	Nil	8	67
	One	4	33

Perceived Family and Organisational Support

In-depth interviews with the participants revealed common themes, and each theme is examined through the lens of both informal and formal institutional support. The results revealed their perceptions and standpoints in having a supportive family and a supportive organisation (see Table 2).

Table 2: Perceived Family and Organisational Support

Themes	Sub-themes
Infrastructural Modification	• Infrastructural adjustments at home • Infrastructural changes at public places • Access to transport
Emotional Support	• Care and compassion • Coping strategies
Support to Access Education	• Impart art, skill and scientific education • Information on education • Advocate on educational policies/inclusion
Career Guidance	• Assist to start business • Assist to get loans • Information on job opportunities
Partner Selection	• Aid to build heterosexual relationships • Convention for mate selection

Infrastructural Modifications

Family members play an integral part in making infrastructural modifications, especially at home, and ensure that the living environment is accessible and comfortable. Family makes the effort to customise infrastructure in the kitchen, bedrooms and bathrooms, by lowering the switchboards, door handles, countertops, cots and clotheslines. However, the study results revealed that family support towards making infrastructural changes at home depends on two major factors. A considerably wealthy family can afford to modify the home on par with the height of the person with dwarfism. Also, a family composed of more than two individuals with dwarfism is more likely to make infrastructural changes.

> *"…My wife loves to cook and since she spends most of her time in the kitchen, for her convenience, I have lowered the tabletop and dishwashing sinks. We share similar life experiences as persons with dwarfism, and so it's easy for me to understand her needs and modifying the kitchen was the initial step taken. We intend to renovate the entire house to our height very soon…"* (P6: Employed male).

However, families that cannot afford to make modifications extend their support by placing step stools and sticks to get onto or to reach something placed at a height. In public places, the family members assist the individuals with dwarfism to make use of available amenities. Transportation assistance from family members seems to be invaluable, such as accompanying them during travel, driving them to their destinations, and making travel arrangements. Extensive support is provided within the home and outside, by helping them complete their household chores and even accompanying them to accomplish their outside tasks.

> *"… I work for a private company, and I commute to the office by local train regularly. I will have to wait for hours to get onto a less crowded compartment as I face difficulty in breathing when jammed in crowd. Knowing this, my brother volunteered to drop me to office in spite of his busy schedules. I feel really blessed to have an understanding brother like him…"* (P2: Unmarried male).

The organisation working exclusively for people with dwarfism is focussed on building an inclusive society that accommodates people of different shapes and sizes. Respondents stated that the personal experiences in relation to the barriers in accessing public amenities, are conveyed among the members of the organisation.

The shared thoughts are then discussed in the forum to contemplate potential adjustments. Such efforts from the organisation have begun to bring about infrastructural changes in the employment sector, in educational institutions, restaurants and places of entertainment, specifically, had initiated modification in the seating arrangements. Locating the infrastructural difficulties encountered in public places, the organisation advocates it to the existing governmental bodies and expects constructive modifications.

> *"… I avoid visiting a restaurant mainly because the seating arrangements and hand washing cabinets are placed at a height unreachable to me. I shared this with one of my member friends of the organisation, during a casual conversation. This incident initiated them to visit that particular restaurant and advocated them to modify the amenities there. Now, people like me can visit and enjoy food there peacefully as the infrastructure in that restaurant has become disability friendly…"* (P10: Unmarried woman).

Emotional Support

For a person with dwarfism, family must handle the caregiving role with caution. Apart from giving practical help to alleviate their daily lives, it is equally important to address their emotional needs. Respondents emphasised that living with the condition of dwarfism itself is stressful, and they often go through the problem of low self-esteem. These depressive spells are managed through the efforts of family members by fostering open communication, spending quality time, acknowledging their ideas and empathising with them.

> *"… I lost my husband due to HIV and that was the most difficult phase of my life. This incident put me under depression, had nightmares of my future, had sleepless nights, and was uncertain of my future. Later, my mother started to sleep with me and whenever I woke in the middle of night, she used to sit along with me and listen to my grief. She helped me to accept the reality and motivated me constantly. Thanks to her* (she teared up) *…"* (P8: Widow).

At the same time a few respondents stated that their emotional needs are not taken care of by family members. During periods of hopelessness, the family members had failed to address their need and provide emotional back up. They perceived that their family members bully them sometimes, by using derogatory phrases and passing unsolicited negative comments. This gave rise to frustration, which gradually lead to isolation from the entire family unit.

> *"…I am the eldest son of my family, and I was so desperate of being not able to find a partner of my own preference. My family never empathised with my situation; rather they used statements like 'nobody will volunteer to marry a guy like you'. Whenever I hear such sentences, I regret for being born like this…"* (P3: Unmarried man).

Since the members of the Dwarfism Welfare Association undergo similar life experiences, they get a significant degree of emotional support from one another. Respondents claimed that they frequently encounter stigmatisation, body shaming, and stares from the public, all of which have a negative impact on their emotional stability. By affiliating themselves with the organisation, the essential strategies to overcome such negative experiences are brought to light. That, in turn, has certainly brought a positive change to their lives, such that the fear of uncertainty has been completely struck down. They are reassured that in time of hardships they can rely on the members of the organisation for emotional assistance.

> *"…I was an introvert and the fear of being negatively judged led me to stay indoors. Due to the compulsion of my neighbour (visually challenged), I joined as a member in Tamil Nadu Dwarfism Welfare Association. There I made a great friend who stands by me during the toughest times. Whenever I get stressed, she is my go-to person, she knew to bring me back to track and help me gain positivity…"* (P12: Unemployed woman).

Support to Access Education

Respondents stated that their families never compromised on educating them and ensured that their disability status should never be a barrier in receiving education. The assistance from family seems to be crucial especially during the transition period, such as moving from one grade to the other or moving from one institute to another. Family makes an effort to gather information regarding the availability of different disciplines of study, collaborates with teachers, and assists in the decision-making process.

> *"... In addition to dwarfism, I also have an issue with my spine and that is why I can't walk. I very well remember my dad carrying me on his shoulders daily to my school. Because I was a female with disability, people around advised my dad to discontinue my education. Yet, he was very particular that my disability should never stop me from attaining quality education. I am a B.Ed graduate*

> *and the only reason for my success is my dad …"* (P10: An undergraduate female).

Apart from providing formal education, the family also focusses on imparting life skills and social skills necessary for day-to-day life. Emphasis on participation in extracurricular activities that align with their personal interests, like sports, singing, joining the scouts, etc. are taken care. Families strongly believe that people with dwarfism are completely capable of contributing to the community through acquisition of knowledge.

> *"…I was subjected to constant criticism for my height and my elder brother supported me so much that he made me learn a traditional dance form named 'Marakkalaattam' – which is performed by standing on a wooden stilt that projects me as a tall woman…"* (P7: 27-year-old female).

However, the ignorance of parents in comprehending the importance of education has led to a large number of dropouts at secondary school level. The educational qualifications and exposure of the parents, to an extent, influence the educational attainment of people with dwarfism. Financial status of the family also remains as an unavoidable element in determining the quality of education provided.

> *"… My classmates often bullied me for my height, and I gradually started to lose interest in going to classes. My parents never knew the importance of education and they never forced me to continue my education. Back then I didn't think of the disadvantages of discontinuing my studies, but now I deeply regret..."* (P5: Male participant).

People with dwarfism did not have the privilege of being accommodated in courses like catering, medicine, architecture, physical education and, in particular, those streams where laboratory work is involved. They are unable to opt the courses they desire, by virtue of their disability status. In this regard the welfare organisation plays a significant role in advocating inclusive education policies, promoting equal opportunities and striving to remove the environmental barriers that hinder access to education. Through counselling and mentoring, the organisation provides individualised support to overcome the challenges in attaining education. Furthermore, it concentrates on providing guidance and information from educated professionals to choose the appropriate discipline, while also providing financial assistance to those from low-income families.

> *"… After the completion of my undergraduate course, I was directionless, as I was the first graduate in my family. When I approached the organisation*

> *for help, they linked me to an IT professional and he instructed me to purse a diploma course related to software. That piece of guidance has brought me this far and now I work for a start-up in my hometown…"* (P4: Unmarried male).

Career Guidance

Career guidance is a lifelong process that aids in the financial independence of people with dwarfism. Right from childhood the family encourages them to engage in activities that help to discover their talents, interests and passion. Additionally, it assists them to embrace their uniqueness, rather than focussing on limitations, and celebrates their achievements and milestones. Family equips them with appropriate skills to enhance social competence and supports them to become financially self-reliant. People with dwarfism and their families constantly get updated on the employment opportunities by associating with professionals in their field of interest. Nonetheless, a considerably wealthy family would support them financially to start a business in line with their interest and capability.

> *"... My brother is an electrician and he used to take me to his workplace every day and taught me from scratch on how the system works. I studied only till 8th grade and through his support I have now become an electrician, and under me 8 average- heighted people work…"* (P1: Employed male).

There was evidence of ineffective families that failed to assist their family member with dwarfism in establishing a career. Lack of family support in career guidance resulted from factors such as unawareness of available opportunities, being overprotective, having difficulty in making informed decisions regarding jobs, and misconceptions about the potential of people with dwarfism.

> *"…Though I completed my under-graduation programme, people are reluctant to provide me a job. My younger brother is a HR Manager in a multinational company, yet he refuses to refer me to his clients. When my own family members abandon me, I feel so depressed..."* (P3: Unemployed male).

Over the years people with dwarfism are affixed with the role of entertainers, especially in the circus and movies. The welfare organisation works extensively to bring about changes in the stereotypical jobs made available to them. To empower them, the organisation assists in finding suitable job opportunities by establishing connections with those companies committed to diversity and inclusion. With the support of governmental bodies, the organisation avail loans to them to start their own businesses and encourages members to start small-scale businesses among themselves. Support and resources for business planning and management are offered by the organisation. Most significantly, the ambiguity around employment for a person with dwarfism is resolved by approaching the organisation.

> *"... I worked in a private supermarket as cashier and the organisation forwarded me an employment poster of a leading Multinational Company inviting physically challenged people to take part in the recruitment process and I'm currently working for the same as data entry operator..."* (P11: 35-year-old female).

Partner Selection

Respondents stated that like other people, they too desire to marry and start families of their own. Yet, the societal norm is that, in order to marry, the criteria of desirability should be met. Considering them as undesirable and unfit, society is not keen to engage in marital relationships with them. Families strive to find partners for individuals with dwarfism with the aid of arbitrators and matrimonial sites.

> *"… Since I was firstborn, my parents started to look for a groom immediately after my schooling. My father's friend came with the proposal of a guy who has hearing impairment. We met each other and when he gave his consent of marrying me, even I was okay with it…"* (P11: Employed married woman).

However, when it comes to romantic relationships, there are families that impose their personal preferences rather than respecting the decisions of people with dwarfism. Respondents feel that their families must create a non-judgemental space whereby their wishes are discussed and respected.

> *"… My family members, with the help of an arbitrator tried looking for a partner for me. When it didn't work, they chose a girl who is my relative. The problem is I'm not okay with her and neither is she okay with me. Yet both our families are compelling us to marry each other. I really don't know where this is heading…"* (P4: Unmarried male).

From its end, the organisation organises a convention by inviting the eligible bachelors to meet suitable partners for heterosexual relationships and has thus simplified the process of partner selection. The consent of both the individual and the family is taken into consideration in the matter.

> *"...... I met my husband in the matrimonial convention; we liked each other and with the support of our family members we got married and have a non-dwarf girl child"* (P9: Married female).

DISCUSSION

The qualitative nature of this study provided an opportunity to analyse the common patterns of family and organisational support among people with dwarfism, as perceived by them. Family is an integral social institution with the capacity to influence the behaviour of a person with dwarfism in a positive way and provide support to enhance their quality of life (Pfeiffer & Albon, 2022). The process of family support begins by accepting them despite their disability status, which in turn builds a sense of belongingness (King et al, 2006). The study themes indicated the significance of support extended by family members, in the aspects of infrastructural, emotional, educational, career and partner selection processes, in order to foster their resilience. Delving deeper into family support, parents play a significant role in strengthening their social competencies through inculcating appropriate skills. Interrelated with this, across their life span, is support from siblings who assume greater family caregiving roles when ageing parents are no longer able to provide support (Arnold et al, 2012). Thereupon, intimate partner relationships allow them to expose their thoughts freely and support is manifested through mutual trust and emotional bonding (Abed et al, 2015). In all this, the economic and social statuses of the family remain as major determinants in influencing the support mechanism. Counterproductive family support is displayed among low-income families, and they exhibit dominance and neglect towards people with dwarfism (Shah, 2010).

Similarly, the support from the organisation for people with dwarfism plays an indispensable role in multiplying their social relationships and networks. Interactions with people of similar experiences elicit better advice and strategies that, when implemented successfully, help them to enhance their self-efficacy. From this study, it is evident that people with dwarfism associate themselves with 'Tamil Nadu Dwarfism Welfare Association' for various reasons: to build social connections, for partner selection and to alleviate their social issues. ' The Little People of America' (LPI) and 'Dwarf Athletic Association of America' (DAAA), are a few examples of welfare associations that are functioning exclusively for people with dwarfism, to enhance their daily living and to promote athletic competition respectively. In spite of the advantages of being part of the organisation, large number of people with dwarfism are yet to associate themselves with it. They are reluctant because of the constant fear of being negatively judged and the deep-rooted internalised stigma that has been experienced. Also, it appears that a lot of them are unaware of this organisation, its functioning and significance. It is high time to sensitise these people about the importance and benefits of associating themselves with the welfare organisation. In a nutshell, both family and organisational support are regarded as essential sources of support to enhance their quality of life.

Limitations of the Study

- Measuring support was challenging for the authors as it encompasses a range of different types of support like emotional, financial, instrumental, etc., and the participants perceive and value support differently.
- Since the authors focused on understanding the perspectives of members of the organisation, it is difficult to generalise the findings to non-members of the organisation.
- The authors faced quite a few rejections from people with dwarfism as they were anxious and apprehensive about taking part in the in-depth interview.

CONCLUSION

The study focussed on the perceived family and organisational support extended to people with dwarfism. This support is considered as a major resource in helping to combat their day-to-day challenges. Support from family is evidently both constructive and destructive and is shaped on the basis of the socio-economic status of the entire family. In contrast, the support from the welfare organisation is perceived to provide positive assistance for their empowerment. Therefore, associating themselves with the organisation for dwarfism will certainly be productive in many aspects.

Implications of the Study

- Findings from the research on perceived family and organisational support of people with dwarfism will aid future researchers to extend the scope in understanding their livelihood challenges from the context of an unsupportive environment.

- Counselling and support on the needs and challenges should be given to primary caregivers to better understand the experiences of people with dwarfism.
- The organisations working with people with dwarfism can advocate to policy makers on the development and enforcement of accessible standards in public spaces, public buildings and transportation; also to promote inclusive educational and employment policies.

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