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Living through Disability, a Caregiver's Perspective on Development: Phenomenological Explorations of Disability and Insights on 'Inclusive Development'

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ABSTRACT

The paper is an attempt to construct the lived experiences of the caregivers of children with Autism Spectrum Disorder. The disability of a child has a profound influence on the quality of life of a family especially the care-givers. Coping with this phenomenon in one's life leads to a paradigm shift in one's life's priorities. A redefining of meanings and priorities of one's life unveils as one finds oneself within a process of re-socialization due to the experience of disability. The paper has attempted to use the phenomenological perspective to understand the structure of caregiving, the themes have been designed into: autism as deviance, coping with denial (fear, superstition) and social stigma, accessing medico-therapeutic services, adaptation to a new 'routine' and life-priorities, development of resilience, faith and happiness (thriving within the context of disability), trying to understand and explore various institutional and non-institutional factors that give rise to these experiences. The already published experiences of different caregiver categories have been used to examine the author's own lived experience as a caregiver. It has been found that although there is a universality/commonness to the autism caregiving experience but the socio-cultural and religious contexts within which these are situated and the socio-economic profile of the caregivers constitute unique differences in the entire experience. Values like Brahminism also impact the entire experience. The most important factor however is the availability and accessibility of medico-therapeutic infrastructure within one's locality that shapes the autism care-giving experience according to the author. This underscores the importance of the state machinery (support systems) to aid policy.

According the World Health Organization, an estimated 1.3 billion people experience significant disability. This represents 16% of the world's population, or 1 in 6 of us. They face many health inequities.[1]About 1 in 100 children has autism. The abilities and needs of autistic children vary and can change over time, some of them have severe disabilities and require life-long care and support.[2]

Health inequities that these people face arise from structural barriers encountered by persons with disabilities, including problem of access, expression, stigma, discrimination, poverty, exclusion from education and employment, and barriers faced in the health system itself. Thus, it can be summarized as exclusion.[3]

THEORETICAL AND METHODOLOGICAL PERSPECTIVE

The debate surrounding the importance of objectivity versus subjectivity[4], within the domain of lived experiences of subjects within sociology which relies on the variety of contexts within which meanings are constructed and negotiated.

Insider Versus Outsider approach in research[5]: The Author is an insider to the group under study, single parent, to a 7-year-old autistic child, an academician. The study did not originate in a day, the authors own

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[1] https://www.who.int/news-room/fact-sheets/detail/disability-and-health, accessed on 28.03.2025

[2] https://www.who.int/news-room/fact-sheets/detail/Autism, accessed on 02.04.2025

[3] cwww.who.int/news-room/fact-sheets/detail/disability-and-health, accessed on 28.03.2025

[4] https://methods.sagepub.com/book/mono/objectivity-and subjectivity-in-social-research/toc, accessed on 08.04.2025

lived experiences have fueled and given direction to the development of the study. Participant observation, in-depth interviews, have been interpreted with the use verstehen-subjective understanding, use of introspection and empathy. It has been used to develop a deeper understanding of '*disability*,' 'disability communication' 'autism spectrum disorder', 'caregivers', 'stigma', 'resilience' 'purpose', 'work life balance', 'exhaustion', 'stagnation'

Qualitative research questions display the desire to explore or describe phenomena. Qualitative research seeks the lived experience, the personal experiences, the understandings, the meanings, and the stories associated with the concepts present in our study.[6] Phenomenology is a form of qualitative research that focuses on the study of an individual's lived experiences within the world.[7]

It is however, important to interrogate one's personal experience (standpoint) vis a vis objective knowledge that already exists within the domain. This interaction and examination of this process which will unfold as the discussion within the papers unfolds, will lead to understanding how much of personal caregiving experiences are common universal experiences and the uniquely personal experiences of the 'insider' researcher.

Schutz incorporated Weber's concept of verstehen (subjective understanding). For Schutz, the meaning that the individual imparts to situations in everyday life is of prime importance, he puts the spotlight on the individual's own definition of the situation. Schutz says that in these situations, people are acting on the basis of taken-for-granted assumptions about reality. They suspend doubts that things might be otherwise, and interaction proceeds on the assumption of the reciprocity of perspectives [8] Hermeneutic Phenomenology: Focuses on the interpretation of experiences within the context of the individual's lifeworld and culture.

How does Giddens concept of 'routine' explain the researchers's lived experiences?

The dynamic interaction between structure and agency (structuration theory) structures as constraints on human action and lived experience. The same structures also human rise to human agency that challenge these constraints- structure as medium as well as outcome. Routine reinforces/creates social structures like social norms, individuals can either reinforce of challenge the structures through the exercise of agency- role of de-routinization and transformation: thriving in spite of social expectations of painful existence (exclusion through the experience of disability

Objective knowledge (already published) on care-giving experience within the domain: A literature review of both published articles which describe the lived experiences of care-givers of children with ASD has been conducted, wherein narratives of lived experiences of different care-givers handling ASD children have been documented and categorized within structures of the phenomenological perspective. In this way personal subjective experiences of the researcher have been juxtaposed vis a vis the experiences of others within society. According to Ma Rosario L. Nepomuceno, lived experiences of caregiving for children with ASD can be divided into the following themes:[9]

- Facing Diagnosis Challenges
    - Having limited knowledge about ASD
- Handling the stress of care-giving
    - Handling physical stress
    - Handling emotional stress
- Holding on to Faith
    - Gaining Confidence
    - Finding Meaning through Spirituality

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[5] https://nasenjournals.onlinelibrary.wiley.com/doi/full/10.1111/1467-8578.12426, accessed on 08.04.2025

[6] https://resources.nu.edu/researchtools/qualitativeresearchquestions#:~:text=Qualitative%20research%20seeks%20the%20lived,making%20assumptions%20about%20our%20sample, accessed on 13.09.2024

[7] Wallace, A. R., & Wolf, A. (1995). Contemporary Sociological Theory: Continuing the Classical Tradition (4th ed.). Englewood Cliffs, NJ: Prentice Hall.

[8] Wallace, A. R., & Wolf, A. (1995)

[9] Ma Rosario L. Nepomuceno, Psych Educ, Document ID: PEMJ0, doi: 10.5281/zenodo.6819669, ISSN 2822-4353

- Growing Holistically
    - Broadening the sense of understanding
    - Acceptance of family member’s condition
    - Gaining a greater sense of fulfillment

Joyce Ann B. Jordan[10] used Interpretative Phenomenological Analysis (IPA) to make sense of the Lived experiences of six caregiving parents of children with Autism. During the cross analysis, the following themes emerged:

- Process of Seeking for Intervention Program have three phases:
    - the pre-seeking phase,
    - actual seeking phase, and
    - securing an intervention phase;
- Sense Making Process of Parents are
    - Therapy as Integral and
    - Therapy as Specialist-Guided;
- Parental Struggles in Therapy includes
    - Time Management,
    - Therapy Expenses,
    - Therapy-Client Match, and
    - Therapy Location Proximity; and
- the Contributing Factors to Parents’ Motivation are
    - Parental Love,
    - Parental Responsibilities,
    - Therapy Progress, and
    - Hopeful Outcomes.

Author’s observation: As a caregiver, the themes successfully draw an outline of the caregiving process at a middle- class level, there is a definite universality to evolution of the care-giving process but these experiences are greatly shaped by caste, class and cultural contexts. The study by Anderson resonates with the author’s lived experience as a single divorced caregiver working mother. The role played by the maternal grandparents is very important to the entire process of caregiving, every step of the caregiving journey and still in continuation. Generation gap

Connie Anderson her survey of grand-parents as care-givers of autistic children, found maternal grandparents are active participants within the caregiving process of autistic children. They are found to be provide strong support to primary care-givers in advisory, financial and emotional capacity. Some of them are actively gaining knowledge, engaging awareness generation and advocacy. They were empathetic to the Autistic child/children despite their demographic and technological limitations. These grand-parents are not only concerned about the ASD child/children, but also the care-giver who is their adult child/children. Some of them were proud of the way their adult children had coped with the care-giving process and ‘evolved as better human beings’ due to the process. There are instances of conflict of grand-parents with adult children who are new to the care-giving process. Many of them remain in advisory capacity to the care-giving process alone. They were in many cases the first to identify anomalies within the child’s development process. Other’s normally thought the developmental delays were quite normal, and were shocked to find diagnostic outcomes.

Life- world of a care-giver with a child with ASD: Caregivers of children with intellectual disability especially those within the autism spectrum disorder find themselves going through unconventional experiences arising out of the special needs of these children. Hyperactivity, Non-verbality, Meltdowns, hyper sensitivity, inability to perform daily activities of self-care and hygiene, inability to communicate one’s lived

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[10] Joyce Ann B. Jordan, Psych Educ, 2025, 31(3): 348-369, Document ID:2025PEMJ2966, doi:10.5281/zenodo.14750188, ISSN 2822-4353

experiences of abuse and neglect make it difficult to depend on external support mechanisms wholeheartedly. The paper is an attempt to understand the lived experiences of the caregivers (includes primarily mothers- self and others, published studies on the same issue of ASD children in relation to everyday challenges of work life balance, access to development facilities for Autistic children.

A normal care-givers life begins with attending to the needs of the special child, to the extent the social process do give them exemption to attend to the special competing needs arising within their lives. Normal routine is constructed with expectations like visit to academic institutions, spend time at the same, be vigilant at all times towards the child's needs and caregiving. Intellectual disability of a child brings unprecedented changes into a care-givers life. The realization that the child is 'not normal' and that the family will not have a 'normal' future exposes that social obsession with 'normality/fitting in' to have a routine life as anticipatory socialization trains people to want. The break with continuity with our 'aspirations', 'lifestyle' and 'social identification' that this situation creates shows the importance of conformity with social patterns and traditions.

'Disability is all about living life with a little ingenuity and creativity'. Disability marks a departure from tradition and hence becomes a source of anxiety for the care givers and family members. The children find themselves in a unique predicament,' what is it that they do, that others find so unacceptable'. This break from social routines is a difficult adaptation for most care givers also the child concerned. The exercise of creativity in life is not always desirable as it labels one as 'deviant' and hence the adaptation of families to the special needs of such a child/children may render them 'isolated' or ostracized as earlier studies have shown.

Disability marks an increase in the sources of expenditure, yet the sources of income/promotion/additional income generation become limited. This adversely affects the life of the caregivers. It is a social mandate to abandon career aspirations and higher income aspirations when faced with situations like this. The normal expenditure for caregiving of a normal child to that of an intellectually challenged child might see an increase of 4-5 times depending on the nature and intensity of the disability. Apart from special school fees, system of transport, occupational therapy, speech therapy, behavioral therapy, sessions with special educators, medical expenses and in many cases (if the care giver is a single parent, a caretaker also needs to be hired), investment in special sports training, music training etc. it increases expenditure

It changes the way people perceives one or even self- concept might be affected with this idea of imperfection, flawed and sinner too might form in the heart of the care giver. The break from normality, not having a normal child even leads to medical investigation as to what might be the cause of the 'pathology' societal attitudes suggest 'what might have gone wrong during the pregnancy, the politics of shifting the blame for 'genetic anomaly' to each other.

Autism As Deviance: Societal Attitudes towards disability: The experiences of the caregivers of children with autism spectrum disorder can be viewed as a social extension of the idea of 'disability, because people with autism have a wide range of symptoms which can include differences in social and communication behaviors, intellectual disabilities, and other physical and mental conditions. People with autism also have a wide range of health care and service needs. Research shows that access to needed services and supports early in life can promote people's health and well-being over the long term.[11]

The disability extends to the care-givers in the sense that it includes the idea of them being no longer considered suitable to normal societal life which includes one's aspirations in life both in terms of career success or a vibrant happy life. They are expected (especially if one is a female parent/caregiver) to lead a marginalized social existence, dedicate their life and time to the pursuit of achievement of 'normality' in their ward's behavior through medico- therapeutic interventions. It leads to isolation and frustration. The idea of 'routine' gets tossed around, the struggle with executing the most simple acts of leisure and socialization due the child's lack to ability to adapt or worse 'a meltdown' over a period of time leads to the society avoiding such families, and the families avoiding the 'humiliation' of socialization. Guests rarely visit such homes. Invitations for special auspicious events reduce for such care-givers and their children. Play dates never take place, parents of normal children even very close relatives like siblings ensure that there is minimum mingling

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[11] https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd, accessed on 07.04.2025

between the ‘normal’ child and the ‘special’ cousin so that the effect doesn’t rub off. The process of social construction of ‘Dayin’ ‘tona-todka’ ‘ashubh’ is associated with the primary care-giver. The author being a divorced mother with a ASD child is viewed as a ‘ witch’ and referred to as such by primary relatives. Simple acts of meditation are labelled as ‘witchcraft’.

Sympathy versus exclusion- criticism by family – the care giver becomes responsible for the child’s conduct or misconduct and hence by association the idea of disability expands to the mother. Genes? Autistic mother? Failure to give birth to normal children, failure to train them adequately to turn them normal-like or conformist. It can affect the family’s social position and within the ‘arrange marriage market’ in India.

The experience of disability by extension spreads to the whole family. The problem is the idea of ‘normality’ expectations regarding the normal family situation, investment of resources, the idea of leisure, social interaction, social mingling which inevitably change as the routine of life changes not only for the individual concerned but for the entire family. It thus, leads to downward social mobility for the family for which the ‘care-giver mother’ is held responsible and similar to a widow is expected to live in austerity and devote her life to penance apart from bread-winning and caregiving.

Learning to deal with ‘meltdown’: catastrophe to routine

What is a meltdown? Is it a tantrum? According to behavioral experts, temper tantrums can be violent but they usually are goal-oriented activity among normal children. An autistic child is frustrated due to sensory imbalance, stimulation or overload causing pain and discomfort hence it is not a goal oriented activity. Meltdowns are viewed as major inconveniences by the family and society. Initial reaction is care, concern leading to irritability and care-giver blaming for not adequately ‘handling’ the situation.[12]

Behavioral experts and therapists suggest isolation in a safe environment and no stimuli for the child until it overcomes the sensory discomfort (it should be left alone just ensuring external safety until the period of frustration subsides.) family members deem such conduct displayed by the caregiver as ‘neglect’ and the cultural conditioning of the care-giver also leads to internal dilemmas and value –conflict. Thus, lived experiences of meltdowns of children can be extremely traumatic for the parents and care-givers as well. The screaming, violence inflicted on others and on self-threaten the physical mental and social wellbeing of all concerned. There is gradual acceptance and learning to deal with such situations on the part of the caregivers. However the initial stage is very chaotic and confusing for all. There is dependence on therapy, therapists tend to give helpful strategies and aids to deal with the situation but the pain of looking at a child suffering and violent expression of its emotions makes people around it sad and eventually pain gives way to a pretense of ‘non-challenge’

Government hospital infrastructure are not children friendly. Visit to general/specialized of health care institutions are traumatic, chaotic and energy-draining. Desperate hope for a cure gets shattered once the final diagnosis is over. Autism has no cure. After decades of intervention some management of those symptoms may be achieved. Such diagnosis often meets a variety of reactions one the part of the parents- disbelief, shock, pain, defiance and gradual acceptance. Acceptance happens when one refers to those social recipes[13] when one comes in contact with similar people who are facing similar situations. One in every 54 children are autistic.[14]

Coping With Denial (Fear, Superstition) and Social Stigma: Lack of knowledge about ASD and its onset can lead to misunderstanding and denial within the primary care-givers. Initially the developmental delays are interpreted as ‘normal’ and once the meltdowns begin often the people like the care-takers of the child, relatives, neighbors suggest occult solutions, the inexplicability of certain situations and the denial to accept ‘disability’ within the family lead parents to visit temples, quacks, spiritual gurus, mazhaars in search of ‘solutions. Witchcraft is often an accepted explanation, which leads to pujas, donations and havan for griha

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[12] https://autismawarenesscentre.com/what-is-the-difference-between-a-tantrum-and-an-autistic-meltdown/ accessed on 28.03.2025

[13] Wallace, A. R., & Wolf, A. (1995)

[14] https://autismcenter.org/prevalence-autism-increases-10-1-54-children/accessed on 28.03.2025

shanti. Cultural practices like ‘aakhoi tula’ before local deities (numerous deities and temples claim to specialize in help children speak their first words if the practices prescribed are sincerely followed, thereafter follows a period of belief in quacks and black magic and seeking guidance to avoid any serious problem while simultaneously seeking medical interventions in terms of diagnosis, detection and therapy. Usually, Initial reaction to delayed development indicators is normal seeking medico-social interventions.

The fear of an uncertain future for which there is preparedness, the karma angle of looking at one’s experiences. Why me? Why my child? It is a phase every caregiver goes through especially the author who is uniquely placed within Brahminical society and embodies a Brahminical set of values felt a paralytic fear of an unknown future and tried their best to live in denial of her child’s autism.

The wider context of Covid and the non-functioning of therapy and non- availability of medical aid when the child started experiencing ‘meltdowns’ also aided the fear and denial on the part of the author. The delay in communication was a regular feature of the child’s paternal family history and corona induced isolation and enhanced digital exposure were attributed as child’s development delay instead of eye-contact. Rocking, toe-walking, hand flapping was attributed to ‘boredom’ at home.

Accessing Medico-Therapeutic Services:

Access to decent support systems in especially tier 2 cities in India is also a challenge. It is expensive. Therapists generally charge INR Rs.700/- to Rs. 1000/-per hour (2024, Guwahati). The expertise and the therapy infrastructure is not always the best kind. The rising cost of neurological and ASD rehabilitation is part of the narrative of the ever-rising health care expenditure in Guwahati. It is even more difficult to access the best professionals in field. In a tier 2 city there is only 8-10 (such institutions of good quality which is located in the prime locations of the city). The therapy centres usually lack child friendly spaces usually tiny spaces are allocated to therapies for ASD children. Sports is an important part of rehabilitation strategy of ASD and Attention deficit Hyperactivity syndrome.

The period to early observation of symptoms to detection to denial and finally acceptance of the caregivers usually take a long time. The realization that life will never be the same or ‘normal’ leads to changing interpersonal and social dynamics for the parents and social care givers. There is a steady devaluation of one’s social worth. What is most challenging is the inability to ‘manage’ the ‘meltdowns’ of non-verbal children. They tend to be violent during those sessions usually directing their anger and frustration towards the primary caregiver often resulting in significant physical, mental and emotional trauma and exhaustion. This may result in counter violence on the helpless child on a few occasions. What makes it even more difficult is possibly the idea of *‘karma’* children paying for the sins of parents. The idea of karma and religion ca n sometimes make acceptance of the neurodiversity even more difficult for the caregivers.

Parents with children with Cerebral Palsy and other extreme forms of intellectual disability suffer more as their children are dependent on them of basic mobility as well. Inability to form proper postures make the cost of maintenance and daily life difficult and exhausting for caregivers. The shame, the denial and the fear of triggers often cause caregivers to self –isolate for a couple of years. However, the lowering of social value leads to social rejection and ostracism for such families. They rethink their previous lives (almost every caregiver makes such choices at some point of time) and slowly change priorities and seek out similarly placed caregivers of such children and engage in meaningful connections.

Adaptation To a New ‘Routine’ And Life-Priorities:

Care-givers usually end up re-structuring their lives and priorities of life change around the ‘caregiving’ responsibility. It becomes the central focus of life, all other functions and roles and aspects of life can be negotiated around it.

Every care-giver develops their own unique communication system with such vulnerable persons defying logical and societal scripts, simple ability to read an eye contact to understand the need for a drink or bathroom. The ‘ outer world’ versus the ‘rich inner world’ of the care giver and the dependent, they joys, their expression of likes, dislikes, anger, pain discomfort each can easily be conveyed between the parties with surprising ease over a period of time. The inner world of knowing and understanding is not guided by cultural formulae. This might seem weird or strange to the outsiders of the system, but mutual respect, love, trust, emotions, inner knowing between these transform the rich interactions and thus create a comfortable space between them. This results in an aggressive/assertive attempt to defend this understanding at all costs, a soldier like loyalty to the cause. This leads many on a meaningful journey of community service, social work and even volunteering. Hence, it is imperative to include such 'insiders' to the situations while addressing policy requirements of such sections (ever- increasing) within society. How can academic –medical qualifications or bureaucratic authority without any understanding of this rich inner knowing qualify or create policies/schemes which address these scenarios effectively in a sustainable manner.

Thus, institutional support is key and can be seen in the light of Right to life with dignity. Community centers, efficient day-care centers, educational institutions that cater to people with disabilities, should be mandatorily be made part of the regular social infrastructure, appearing with unfailing regularity within every locality and community. The quality of these institutions should also be monitored and managed with undiluted precision.

These institutions can adopt a multi-pronged approached to care-giving, bring together multiple vulnerabilities together to witness the alchemy of collective symbiosis. They can for instance provide help simultaneously to persons with disabilities, elderly, trauma survivors, each with their own needs and abilities can be trained to become participants within these support and rehabilitative processes. These experiences can be therapeutic and can be a wonderful experiment in achieving social good (utopian it may sound) it has tremendous potential to work out for social good. Support staff (regular) and volunteers suitable for such centers can be trained, paid included for care-giving responsibilities. Composite areas of service should be part of localized 'community centers'. It is time to bring the welfare state and corporations together to contribute to the cause of inclusive national development. It is the only way forward. Legendary music composer once quoted Socrates that the perfection is a 'collectivity': conscious and walking together for humanity and never an individual. Creating experiences of 'gratitude' among citizens in situations where they need maximum help, would create human resources willing to exert their full potential for nation's development. The marginalized also deserve their rightful space with the nation's/ society's journey to 'greatness'.

Development Of Resilience, Faith and Happiness (Thriving Within the Context of Disability)

Eventually, once adaptation is made within the context of disability as a central feature of a care-giver and family's life, despite the social consequences, new social support systems are found usually via educational institutions actively engaged in disability education. Some of the institutions ensure every festival is organized within its premises, enabling these families nad caregivers along with their children to feel the spirit of being included with their own uniqueness. Within such structures, one feels included, sometimes a strange gratitude develops at being chosen to care for such special beings with their unique world. The realization that the Autism Spectrum is too diverse and that one's won child is better off in terms of the severity of disability. The author found it difficult to attend regular parents support group session due to the fact of being employed. The author renewed her interest in sociological research after a hiatus of nearly a decade due to coping with challenges of care-giving. Nor was the author an active participant like many other non-employed mothers who were engaged whole heartedly in the child's development process as well as the parent- support group initiatives. However, with the cultivation of faith, resilience develops within both the child and care-giver. The experience revitalizes their outlook in life. The hedonistic leisure activities no longer attract them but the pursuit of meaningfulness in one's life takes precedence. There is a realization that money and power are central to building a secure future for the child, at the same time a spirit of empathy is developed for other children. There is a passion to create better infrastructure of support for similarly placed individuals. There are districts in India where there is no single institution for rehabilitation and therapy of persons with Autistic Spectrum Disorder. When the care-giver looked at social media platforms like YouTube, a lot of research and innovation is recorded but they are majorly located in developed countries. A tier 2 city in India is still better off then many other towns and smaller cities. Yet latest statistics on ASD suggest one in every 54 child is Autistic. This means the current framework of developmental and therapeutic institutions dedicated towards disability education is not enough. The funding that these institutions receive is not enough either. There is a need to constantly be abreast of evolving rehabilitation therapies and train the professionals who can make the 'care-givers' life better. The care-givers have a right to a better quality of life. The institutions dedicated to disability education deserve state of the art infrastructure and skill development. They should be accessible to communities regularly.

CONCLUSION

Most parents although they struggle with care-giving receive a lot of support from grandparents especially in societies like Indian. Usually, the maternal grand-parents play a more active role in providing support and care. They want to do more but fail due to health and resource limitations. Many grandparents sacrifice their old age towards the care and support of their Autistic grand-children. Their lives revolve around the child's success within rehabilitation, coping with evolving challenges. Locally available acre and support groups are key to make the process of care-giving easier for all. Within a distance of every 5 mile or so, it is imperative to situation day-care and disability education institutions. The services should also be provided at subsidized rates to increase accessibility to poor families in society like Indian.

Children with ASD should be treated not as anomalies but beautiful people who in their own way make the world a beautiful place to be in. They deserve every support that the state and society can provide to create true equity within society.