VISION DOCUMENT FOR ACCESS FOR CHILDREN AND ADULTS WITH SPECIAL NEEDS

What can IACP do for ACCESS problems in India?

Theme No.1 of watch words project-2021-2023

Contents

Definition

The oxford dictionary defines access as the means or opportunity to Approach or enter a place or a system or technology. Interestingly it is a noun as well as verb. Wikipedia defines being 'Accessible' means a person with a disability is afforded the opportunity to acquire the ***same information*** (**information about the disability**) engage in the same ***interactions***, (**School and Recreation**) and enjoy the ***same services*** **(Healthcare)** as a person without a disability in an ***equally effective and equally integrated manner***, with substantially ***equivalent ease of use*** **(Assistive technology and accessible spaces).**

As described in the watch word presentation, we have huge barriers and challenges. Some of them like poverty, large population, and unequal rural and urban divide are not in our hands to correct. **We will put the other challenges which can be mitigated as actionable themes on which the core members can plan strategies and solutions.**

Vision

To create a system and framework for facilitating easy access to health care, education, entertainment or recreation, easy entrance to public spaces and transport along with barrier free living spaces to every child, adolescent& adult person with Neuro developmental disorders & support the quality of life of the persons as well as their families.

THE ONLY DISABILITY IN LIFE IS BAD ATTITUDE

Our Mascots

Self-employed Nupur

Nupur is cooking and posing

Parents from all religions celebrating Christmas at District Early Intervention Centre at VVH, B'lore

Arjun's participation in Diwali celebrations

FAMILY& PROFESSIONAL SUPPORT HAS BEEN

THE PILLAR FOR THEIR DEVELOPMENT

Members of Access group

1. Dr. Gopalaswamy Shashikala (Chairperson)
2. Mr. Asis Kumar Ghosh
3. Dr. Shabnam Rangwala
4. Mr. Saravanan Sundarakrishnan
5. Dr.Vimochana K
6. Dr. Kawaljit S Multani
7. Mrs. Sadhana Rathnaparkhi
8. Dr. Puja Dhande
9. Dr. Vandana Giri
10. Dr Senthil
11. Dr. Shalini Modi
12. Dr.Divya Karthik
13. Miss Nupur PIdadi
14. Mr Arjun Modi

MISSION

1. Access to Health care- rural as well as urban [DrShashikala, Dr.Shabnam Rangwala & Dr.Divyakarthik]

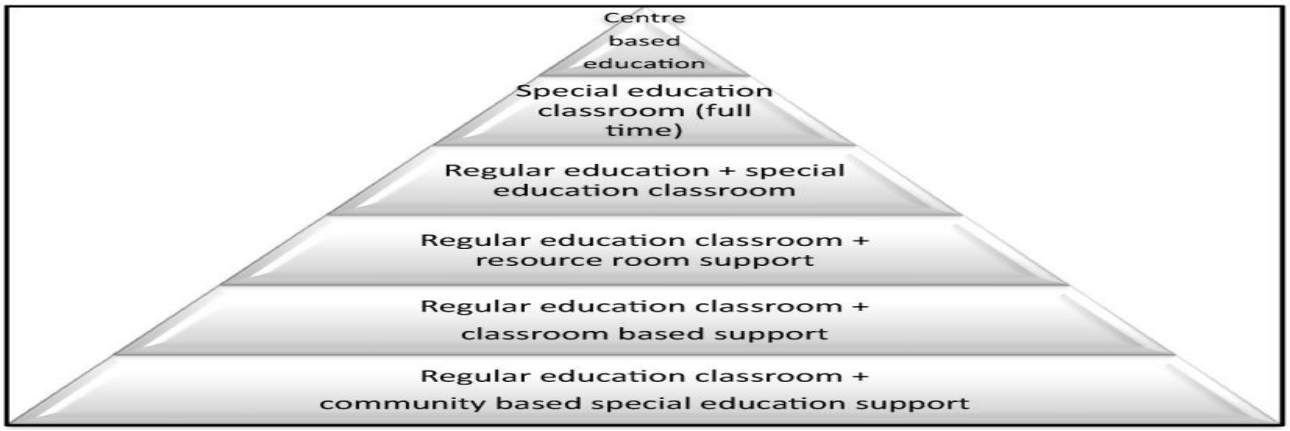
As per Census 2011, in India: out of the 121 crore population, about 2.68 Cr persons are 'disabled' which is 2.21% of the total population. Disability is an important invisible public health problem especially in developing countries like India. The problem will increase in the future because of the increase in the trend of non-communicable diseases and change in age structure with an increase in life Expectancy.

In India, a majority of the disabled resides in rural areas where accessibility, availability, and utilization of rehabilitation services and their cost-effectiveness are the major issues to be considered. Traveling to access health care increases the financial burden. The healthcare industry has not been geared to meet the needs of this vast section of people with disabilities and their specific needs. We have not given enough attention to people with disabilities, but it actively patronizes them as less endowed individuals. Inaccessible hospitals, the staff unaware and untrained to deal with PWDs increase their unmet health needs and they continue to be poor cousins of all health initiatives. Economic, geographical, gender inequalities added to rural-urban divide and cultural influences affect the quality of life of persons with disabilities more and their families too. This creates a vicious circle of not acquiring the right treatment at the right time which increases the severity and discouraging health outcomes.

Just like justice, delayed health care is no health care at all. We intend to participate in vitalising this area & seek practical solutions of reaching the unreached.

2. Access to schools (Dr.Vimochana, Dr.Kawaljit, Mrs. Sadhana Ratnaparkhi, Asis Ghosh)

Children with disabilities constitute 1.7 percent of the total child population[1] in India (State of the Education Report for India: Children with Disabilities, 2019). Despite the existence of a comprehensive policy on education with provisions to make the Indian education system inclusive 75 percent of children with disabilities (CWDs) do not attend schools in India (UNESCO report, July 3, 2019). 27 percent of CWDs never attended any educational institution, as opposed to the overall figure of 17 percent when the entire child population is taken into account[2]. Education is an important tool to achieve good quality of life. The ratio of health care, employment opportunities, income and participation to socioeconomic life are positively associated with the level of education. Disability is a factor that precludes continuing education, access being a single major reason in India. As a consequence its' results increase the load of being socially and economically disadvantaged besides being disabled. This trend may be broken down by increasing the availability of AT in educational institutions, the accessibility and the quality of (special) education to the children with motor and learning difficulties. By mainstreaming children with special needs, their socio-economic development can be significantly improved in order to improve their quality of life.



These are the steps to be followed up. Hand holding & collaboration with SSA to be done at the earliest .Continuation of developmental care in early school days, life skill & vocational training for adolescents which is part of the new education policy should be encouraged. Govt. policy for higher education to specially abled children is already in place& needs advocacy from professionals.

3. Access to technology (Asis Ghosh and Mr.Saravanan)

What is Assistive Technology?

The Assistive Technology is broader term that covers many technologies, devices to support people with disabilities. The AT varies from a low-tech spoon grip to a high-tech computer switch or motorized wheelchairs. The purpose of using AT is to remove the barriers and/or facilitate the users to enable access to activities of daily living, education, information, healthcare facilities, transport, workplace, recreation and sports (UNCRPD, 2006; World Report on Disability, 2011; WHO, 2012).

Use of AT

Assistive technology used by individuals with restricted abilities caused by motor or cognitive impairments in order to perform functions that might otherwise be difficult or impossible. These tools can be modified or customized to suit the user's abilities that enhance or maintain their functional capabilities. AT may provide a wide range of devices that spans from mobility to communication to recreation and across many spheres of life such as academic and social development, self-advocacy, Participation in economic and socio-political development consistent with the goal of full inclusion.

4. RECREATION- (Dr. Puja Dhande and Dr. Vandana Giri)

Recreation is an activity of leisure, leisure being discretionary time. The "need to do something for recreation" is an essential element of human biology and psychology. Recreation is an essential part of human life and finds many different forms which are shaped naturally by individual interests but also by the surrounding social construction.

Recreation is difficult to separate from the general concept of play, which is usually the term for children's recreational activity. Children may playfully imitate activities that reflect the realities of adult life. It has been proposed that play or recreational activities are outlets of our expression of excess energy, channelling it into socially acceptable activities that fulfil individual as well as societal needs. Play is a fundamental part of childhood. Recreational activities can be group or solitary, active or passive, outdoors or indoors.

Persons with disabilities are often excluded from activities that other children take for granted, like making friends, playing with friends, having fun, playing sports and other recreational activities. They are often excluded from many of the things that help children develop and give them opportunities to reach their full potential. Imagine a day in the life of a child with disability; morning chores, (ADLs, brushing, toilet activities, bathing, dressing-grooming) →

School → return home → Therapy 1 and/or Therapy 2 → school work → Eat → sleep

As Dr Ashok Johari has quoted in this editorial in DMCN that," Although there is increasing clinical research in cerebral palsy in India, it remains focused on interventions to reduce impairment; whereas activities, participation, and environmental factors are minimally addressed."

Yet these children have the same right to be included in these activities as all children. Most parents can take a break from parenting responsibilities when their children are playing with friends or involved in leisure activities. Parents of disabled children often do not experience these breaks. Recreation enables children to develop social skills, form friendships, develop physical skills and learn about and become confident in their environment. However, for many disabled children, opportunities are severely restricted.

It gives an Opportunity for children to face challenges, share solutions and rewards, learn new skills within the dynamics of a group. These opportunities provide commonality (e.g. "I'm not the only one with this problem"). Social aspects of doing a positive activity can be as, or even more, important as the activity itself. Peer interaction provides encouragement, acceptance, social skill development, behaviour modification, support, reward and friendship **(having FUN and building FRIENDSHIPS in terms of F- words and enabling PARTICIPATION according to the ICF).** Emphasis is put on teaching family members to use these strategies at home to help Generalization. Promote independence, interaction, and friendship building for families and caregivers. Provide support and reassurance that they are not alone! The opportunity to experience success at the end is a major source of Intrinsic Motivation for children. They know that their efforts will be praised. They will not be judged irrespective of their disability. It has various advantages for children and families.

For children

I. Improved Confidence and Self-esteem
II. Finding self-worth to bring a positive change for self-sustenance
III. Developing hopes to bring a positive change for the society at large

IV. Self-discipline
V. Emotional development.
VI. Improved Behaviour.
VII. Independence or Self dependency.

For family

I. Understand their child's needs and hurdles better.
II. Know how and when to support and when to step back.
III. Get breaks from parenting responsibilities for some time.
IV. Form parents support groups and learn from each other's' experiences.

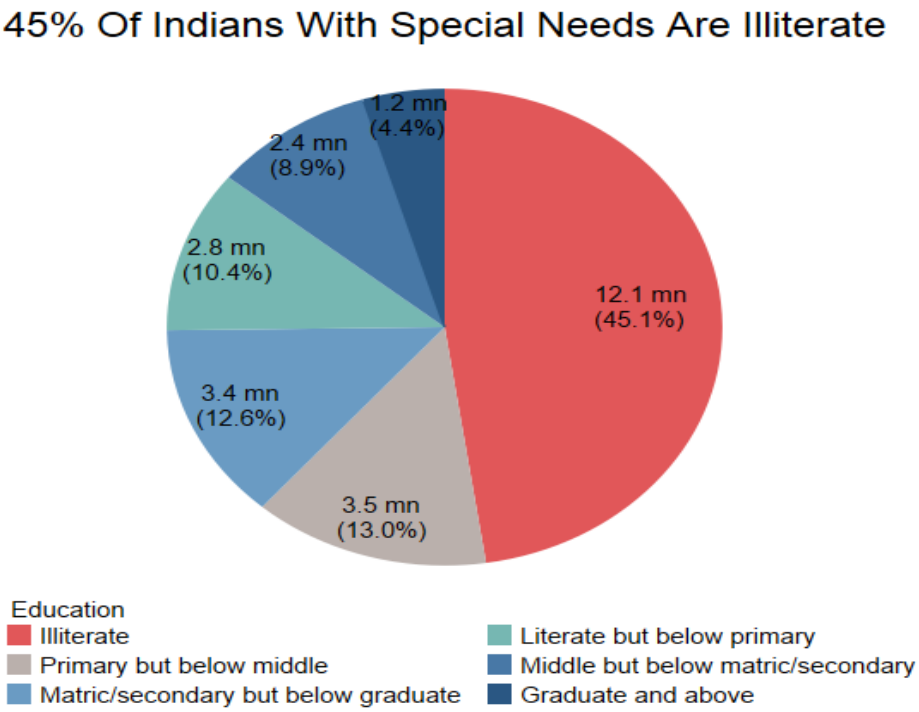
Environmental factors are understood here in terms of WHO's International Classification of Functioning, Disability and Health (ICF). Such factors include products and technologies, services, systems, laws and policies, the natural environment and human-made changes to the environment, support, relationships and attitudes (both individual and societal). These factors may operate as barriers or facilitators of play for children with disabilities.

5. Information (Dr. Dhruv, Dr. G. Shashikala, Mrs. Priya Rout)

"Health in hand" is the present concept in public health. Disability is an invisible public health problem as its impact affects the individual and the family that nurtures him/her.

Health literacy is defined as the degree to which individuals have the capacity to obtain process and understand basic health information and services needed to make appropriate health decisions [US Department of health]. This has to be delivered at all levels with a lifespan approach.

Health disparities: are differences in availing available health services due to inequalities of various kinds: This can be solved only by providing information to the community through all media-visual, printed, AIR , TV etc. Illiteracy & ignorance breeds poverty of health as much as material poverty. This needs correction with the power of right information. Knowledge is power & disability stakeholders need it at all levels from top to bottom.



6. Accessibility (Dr.Shashikala and Dr.Shalini)

- India is a country of significant urban and rural divide. There is a similar divide between health consumers who spend out of their own pockets & those who are entirely dependent on provisions by the government. This causes a health disparity affecting both accessibility and utilisation of available services particularly in rehabilitation**.** Accessibility to spaces both public & private spaces becomes a prey to over crowded cities, huge traffic, poor transport facilities , inaccessible & costly tech help, limited finances
- Enhancing the capacity of all people to obtain, process and understand basic health information and services needed to make appropriate health decisions is dependent on accessibility to these centres & to basic entertainment to keep the restrictions in mobility at bay

Accessible India Campaign (Sugamya Bharat Abhiyan) is a nation-wide Campaign launched by Department of Empowerment of Persons with Disabilities (DEPwD) of Ministry of Social Justice and Empowerment to provide universal accessibility to persons with disabilities. The Sugamya Bharat Abhiyan focuses on developing accessible physical environment, transportation system and Information & communication ecosystem. But this needs interaction and convergence of ideas from all the policy makers, professionals along with the consumers of these services. IACP should play a proactive role in supporting these schemes

Strategies

1 .HEALTH CARE- PLANS

A. We need to join hands with the visionary RBSK programme, the National Health Mission (NHM) began in 2013. Developing, democratic countries need to have this kind of Convergence of ideas between policy makers and technical and academic personnel. Where District Early Intervention Centres (DEICs) are not yet operational, sharing the simplified national data base (NDB) proforma would be a way forward.

As health is a state subject, IACP should shoulder the responsibility of supporting DEICs in offering its academic excellence by innovative partnerships for knowledge brokering by virtual or physical training workshops.

We need to use the Govt. network of ASHA and Anganwadi workers and train them in simple early detection and early intervention modules which are cost effective, scalable and sustainable. Using the IDDEA module of IACP is one such feasible programme in urban as well as rural areas. The existent DEIC training is slightly not in tune with recent perspectives on Early intervention and diagnosis as per the recent ICF and Functionality modules. We could approach NHM with a proposal. As infrastructure and human resource shortage is the biggest challenge, IACP will offer its trans-disciplinary module [IDDEA module] as a feasible option in peripheral areas. Fresh thinking into adult care has to be infused.

B. With disability inclusion made compulsory in medical education, we need to set up a task force and impress upon the MCI of the need to upgrade the training to Culturally & regionally possible modules which have to be part of competency building. Forming a core group of specialists from IAC P & likeminded academies would be a priority.

C. We have large no. of NGOs working in the field who do not have competent health care support and do not follow a homogeneous protocol. Mutual exchange of training & hand holding Opportunities need to be considered. Special care for health services for nutrition, epilepsy care, Hip & bone health, Dental health.

D. **Setting up disability Health data through national database** should be a priority as well as a life span approach to disability care. The database will show the lack of penetration of services geography wise, age & specific disability wise and will promote uniform assessment and management which can be prioritised. Uniform guidelines for early intervention are to be put in place.

E. Access to therapeutic services

In view of the extreme paucity of specialized human resources in our country, there is an urgent need to develop methods to make their access easier for families with children with neurodevelopmental disabilities. Moving services closer to their homes is essential to ensure compliance. Access to basic therapeutic services should be made available at the cluster level or the block level. Providing therapy that is family centered and functional, will support a move towards evidence-based interventions.

IACP should take a lead in guiding National programs such as the RBSK to support these evidence-based interventions moving to the bio-psychosocial model of ICF.

F. Disability certification

Families in rural areas need support in this area. Information brochures and pamphlets in regional language could be created to help them understand the process and the advantages of the same.

The certification process also needs further attention especially for the area of neurodevelopmental disabilities. Networking with the certification authorities should be established to set up protocols for children with multiple disabilities who may be unable to visit the centers.

G. Appropriate school placement after early intervention for 1-6 yr. age group should be the next transition for children. Health care should continue in school setups. Available health care should be scaled up & made sustainable. Special care health services for nutrition, epilepsy , Hip & bone health, Dental health, vision care, mental health care, Coping strategies for PwD parents & siblings ,Life skill training , Reproductive & family healthcare should be provided.

H. Setting up transitional care services for adolescents & adults should be a priority. For every child we see in our clinics, three adults in the community are there who do not receive any health care. This is an anomaly which needs correction. Measures needed are simple & can be included in our well-being clinics promoted by the government.

I. Most important is to develop uniform, ICF based early intervention modules & functional therapies to improve participation, optimality & fun directed which are family centred with life span approach to be developed as a priority. This needs convergence of ideas, innovative, cost effective, culturally relevant thinking & implementation strategies.

2. SCHOOLS

- Create awareness of various disabilities
-
- Identify target group
-
- Provide information on interventions available
-
- Suggest modifications to ease issues

ACTION POINTS OR GOALS – SHORT TERM / LONG TERM

- START WITH PILOTS IN ONE / TWO SCHOOLS OF EACH MEMBER
- ASSIGN RESPONSIBILITIES BASED ON WHAT EACH MEMBER FROM DIVERSE BACKGROUNDS IS COMFORTABLE WITH.

1. **Assess magnitude of target population in schools**
2. To define what the target population is –
   - Not Only Cerebral Palsy/ all disabilities
   - Primary and middle School /High School /[Life skill training] both
3. **Access**
   - To schools
   - Sarva Shikshana Abhiyan
   - Rashtriya Bala Swasthya Karyakrama, Rashtriya kishoreseva karyakrama
4. **Information on Baseline**
   - Projects
   - Human Resource
   - Data of children
5. **Analysis of the data**
   - Strengths
   - Barriers
   - Challenges
6. **Different approaches in different places**
   - Government schools
   - Private schools
   - Special schools

3. Assistive technology

Following are some of the challenges for AT in India

- Families especially belonging to the rural areas are unable to reach the institutions where such products are available
- Acute shortage of qualified and RCI certified professionals handling the AT device
- Inadequate infrastructure such as broken roads and pavements, power outages
- Poor affordability
- Untrained professionals or quacks providing devices to patients via camps which are poor in quality and ill-fitting even though they are free of cost
- Lack of proper service for repair and maintenance and follow ups

Plans

1. AT should be available at an affordable price to enable users belonging to middle and low income families. Users should be provided the recommended AT with Government subsidies/waiver of GST/absolutely free as per the family's income.

2. All educational institutions should allow the users to use AT for educational purpose, to communicate, participate in curricular and extracurricular activities, sports and games (facilitating inclusion!).

3. Review of user's performance with the help of AT and views on user's capacity enhancement to be taken from the stakeholders. Reviews should be done by the providers at a certain interval as decided by them. District rehabilitation centres to be involved and workshops to be organised judiciously to reach out to the rural areas also. Trained and registered professionals only to provide the necessary services to get best outcomes and compliance for users.

Recreation

Key action points on how IACP can help to enable recreation

1. Raising awareness to ensure and empower children's Right to recreation.

2. Recreation across life span.

3. Across various settings such as home, community, school, both indoors and outdoors.

- Screen time can be utilized by the entire family to watch sports, special Olympics, etc. together
- Arrange play dates at each other's homes
- Engage peer and sibling interaction through group games and activities
- Community halls (society club houses) can be utilized for indoor activities
- Use of popular local songs and local games improvised according to the need of PwD's.
- Involve PwDs in community programs/ celebrations and get together
- Make recreation an integral part of the child's daily routine

4. Educating family members, extended family and neighborhood about adaptations of day to day games and activities in which child can participate.

5. Involve local, district and state level organizations for eg (DEIC, RBSK, local NGOs, ASHA workers, who can work on recreational activities)

6. Use of booklets to spread awareness.

7. Each child is unique therefore, design and modify activities according to the needs of PwDs

8. Each person should be given the opportunity to participate irrespective of their disability.

9. Form homogeneous or heterogeneous groups depending on their needs and abilities.

10. Involve neurotypical children and siblings, cousins as peer-players for children with severe involvement (buddy system).

11. Use all festivals and events to promote recreational activities for PwD's.

12. Special screening of films and shows for PwD's at movie theatres also screening of inspirational movies of PwDs to inspire and motivate

13. Screening of sports events such as IPL, soccer games at club houses of housing colonies.

14. Organize virtual games.

15. Celebrate special days to maximize participation of PwD's.

16. Stop overprotection.

17. Respect child's preferences; do not impose your choices on them.

18. Collecting database of institutions and organizations which provide recreational opportunities for PwD's.

19. Collaboration with different travel companies like MakeMy Trip, Trip Advisor for providing pleasant and comfortable trips for PwD's. Air travel, train travel in disabled friendly compartments & buses should be made cost effective.

20. Pooling of ideas across professionals working for recreational activities such as music therapists, arts based therapists, physical instructors, dance and drama therapists

21. Developing resource centers for recreational activities. (Advocacy with the Govt.)

22. Creating equipment and toy libraries

23. Organizing No Screen Days to maximize creativity and individual interest.

24. Developing adapted games and toys.

25. Encourage therapy centers, special schools, etc to make recreation as a routine activity for the PwDs

26. Heritage & tourist attraction sites to provide wheelchairs & permission to wear orthotics should be arranged

27. Use of puppets and storytelling, reading, using visually attractive books and equipments e.g Sa re ga ma mini kids, audio books

Information

Simple Ten /twelve pages Spiral bound Hardbound booklet (Leaf let) that has many pictures each. So in twenty pages we tell as much about Cerebral Palsy namely

1. Cerebral palsy what is it? New definition of CP & ICF, F-words
2. Causes & comorbidities
3. Functioning of brain and other systems,
4. Development in First two years of life, Nature of development
5. Early detection /identification, Functional classification systems
6. Early intervention, neuroplasticity
7. Role of Therapies -Physiotherapy, Occupational therapy and Speech therapy
8. Parents training and Family centred services Communication, Anticipatory guidance and Coping
9. Role of drugs, injections surgeries
10. Role of Orthotics
11. Posture and mobility aids
12. Aging in. Cerebral palsy
13. Health monitoring through lifespan
14. Prevention
15. Parental health & community support
16. Cerebral Palsy so what? -Persons who have blossomed (Achievers).

Similar booklets for Autism, ADHD & SLD should be brought out.

ACCESSIBILITY

Identification of vision abnormalities in children is important & will be possible with a mandatory 6 month vision check for all school children.

1. In Schools, Vision access is very important. As far as possible, the floor should be level.& any change in the levels, viz stairs, entry to a room or exit areas can be highlighted with reflective tapes
2. Have railings in areas where the ground is uneven, like playground or garden areas.
3. The class rooms should be well lit & if possible, spacious to accommodate children according to the size of the room.
4. If children on a wheelchair need to enter or exit, the door size should be slightly larger than a regular than a regular size, approximately 3&1/2 feet
5. Ramps to increase access in areas at different levels.
6. Toilets to be made disabled friendly with railings & room for a wheelchair
7. Having a disabled friendly play area.
8. Improvement of family setting where ever possible.
9. Removing barriers at home needs creativity than spending money. Western style Commodes or hanging ropes in indian style toilets, Nonslip mats in front of wet areas, appropriate bathing adaptations to support independence, ramps if there are steps, removing the traditional thresholds in living spaces, suitable sitting space for wheelchair users & furniture modification to support independent eating, railings at home particularly in front of bathrooms & non furniture & **use universal designs.**
10. Access to play grounds, parks, theatres, malls, shopping and entertainment, Public parking sites for disabled to be made compulsory. Yearly accessibility audit should be arranged with Sugamya Bharat authorities.

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