

Needs of Persons with Severe Intellectual Disabilities

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Do persons with severe intellectual disabilities (ID) have any needs that are different from those of mild or moderate intellectual disabilities? Yes, they do! Persons with severe intellectual disabilities have many needs that go unrecognized. This is a group that has many other disabilities, frequently having communication difficulties, cerebral palsy etc. These are many a times associated with communication difficulties. When communications difficulties are present it poses an obvious problem in understanding needs of persons with severe ID. In India most of the persons with severe intellectual disabilities live with family, hence most important factor remains attitude of family or caregivers towards needs of persons with severe ID. If family acknowledges that a person with severe ID may have needs only then they will try to find out needs and desires. Many a times family may believe that person with severe ID doesn't have any specific needs. Family and caregivers project their thoughts on the person with severe ID rather than acknowledging that they may have different needs.

Some of the needs are basic and physiological, like food, clothing, shelter, and reproduction. These are assumed for all human beings but for person with severe ID all these cannot be considered as basic. Even if some of these needs are met the self determination is not taken care of. Person with severe ID are rarely asked what they want to eat or wear. At the same time, it is important to give limited number of choices else the person with severe ID will not be able to make a decision. Person with ID are not able to impose limits and restrictions on themselves and this results in excessive eating behavior when emotionally disturbed. This brings to focus a need that a structured environment or external boundaries are required.

One important need for all human beings is social relationships or social network especially for persons with severe ID. Usually they have only family members and staff in the institute if they are attending any. They want a social life; want to have friends from opposite gender also. They want to be accepted by others and a feeling of belonging. They need affirmation and need to be taken seriously. Like all people they feel good when appreciated and when they are useful to others (Morisse et al., 2013).

Health care needs of persons with ID are many. Their health may be affected due to associated conditions like Down syndrome with thyroid problems, conditions affected by environment like unhealthy levels of lead and other contaminants, individual behavior like poor dental hygiene, poor nutrition, smoking, and inactivity. There may also be late diagnosis of serious health conditions like cancer and missing of common health conditions like caries. Further often there is inadequate treatment for conditions like depression, recurrent pneumonia, and bowel obstruction. One important limitation in adequate health care delivery can be communication difficulties. Person with severe ID may not have proper vocabulary to express the discomfort they are feeling. When they are examined by a physician there may be difficulty in eliciting clinical findings due to communication difficulties. If persons with severe ID are living in a group home setting and there is a change in caregivers or change in primary care physician, the caregiver or physician may not have access to the previous medical history and it can lead to incorrect information and diagnosis. They may communicate the problem but caregivers may not give adequate attention to the complaint made by them. Often diagnosis of severe

medical condition is made at a very late stage. Late diagnosis of cardiovascular diseases, pneumonia, intestinal obstruction and trauma leads to high mortality. Vision and hearing impairment is frequently missed in these persons. Oral health of persons with severe ID remains poor with many having more missing or decaying teeth. There is less awareness in care staff and family members, who neglect these issues.

Since persons with severe ID depend on their care staff and family members to identify health concerns, to communicate with physicians, and to promote healthy behavior it is important that awareness of family members or care staff is enhance for health issues (Kranh et al, 2006).

Chronic conditions like hypertension, diabetes and arthritis may not get proper attention. Being overweight and obese is more common in those living at home. Metabolic syndrome is common.

Persons with severe ID also need education or training to live meaningfully.

In order to adequately take care of needs of the person with severe ID following steps can be taken:

1. Early identification of level of disability and associated conditions.
2. Frequent health check- ups for persons with severe ID to diagnose associated conditions.
3. Preventive care for life style disorders like nutrition, exercise, oral hygiene.
4. Educating the family and community regarding their needs in various areas.
5. Awareness of health care professionals towards different aspects of their health needs
6. Raising awareness in community towards self determination for persons with severe ID
7. Health care providers for people with intellectual disabilities should adopt a life span approach and take in account the progression of diseases and therapeutic intervention(Evenhuis et al.,2001).

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