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WHAT AFTER ME?

Information to Parents of Persons with
Intellectual Disability

What is Intellectual Disability (ID)?

ID is a condition which affects overall development of the brain starting before the age of 18 years. It was formerly known by different names like mental retardation, mental handicap, etc. Persons with ID have difficulties in different dimensions like intelligence, learning, personal care, adapting to environment, socialization, and communication.

ID is not a 'disease' and hence cannot be 'treated' with medications. Medications are required only if the person with ID has associated psychiatric or medical conditions. Persons with ID require long term psychological and social support to lead an independent, productive and happy life.

The ability of a person with ID to lead an independent life depends on many factors such as severity of the condition, associated medical problems (like autism, cerebral palsy, hearing disability, visual disability, epilepsy, etc.), current abilities, opportunities in the community (e.g. availability of special schools, vocational training centres, job opportunities), social support and life circumstances. Therefore, it is very natural for parents to be concerned about securing future of their ward with ID.

What can a person with ID do?

With appropriate training, persons with mild ID can be employed successfully in a supportive environment, where the nature of work requires practical abilities. Persons with moderate ID can do some simple practical work, if tasks are carefully structured under skilled supervision. Persons with severe ID can become largely independent in their daily activities and may be able to do simple household chores.

you may kindly contact your District Disability Welfare Officer (DDWO).

Karnataka Parents Association for Mentally Retarded Citizens (KPAMRC), an organization started by parents with intellectually disabled children in Bangalore runs a long stay residential care facility for their wards by pooling their resources together. Caregivers may check if similar facilities are available in their locality. If such facilities are not available, it is a good idea for the caregivers to come together to start similar resources.

How can parents help their ward with ID during their lifetime?

Parents of a ward having ID need to understand the condition better to plan for the future. The following broad guidelines may be helpful for parents while working with their ward with ID:

- **Create a supportive environment:** Let the person with ID feel wanted and loved by the family.
- **Develop competencies:** The person with mild/ moderate ID can be guided through a series of carefully planned steps to shoulder responsibilities in a supportive environment. The individuals can be encouraged to participate and learn household chores (like cleaning, washing, purchasing groceries/ vegetables, simple cooking). Parents can encourage their ward with mild/ moderate ID to handle money (update passbook, withdraw money from ATM and pay the neighboring shopkeeper) under their supervision and empower them to independently carry out transactions. Participation in social functions involving relatives/ neighbors/ significant others will facilitate interaction of person with ID. These occasions may also break several stereotypes/ negative prejudices associated with ID and spread a positive message.
- **Give opportunities to practice:** It is important that persons with ID are allowed ample opportunities to practice what they have learned. For example, if they have learned to count money, they may be allowed to pay their bills or shop groceries, etc. This way all essential life skills can be taught with proper planning.

Parents need to involve the prospective caregiver in coordination and provision of relevant services to their ward with ID for ensuring continuity of care.

Conclusion

With proper planning, parents can ensure a safe, happy and satisfactory life for their ward with ID after their life time. Parents can achieve this by understanding specific Government policies and availing appropriate schemes in this regard. For further information, kindly contact the District Hospitals and District disability Welfare Offices and/or NIMHANS.

Further Reading

1. Hamza A (Ed). Social Welfare Measures for persons with mental disability. NIMHANS Publication. 2014.
2. Making a Will and Forming a Trust. Psychiatric Rehabilitation services, Department of Psychiatry & Legal Aid Clinic, NIMHANS.
3. Nair S. Empowering parents to deal with sexuality issues mentally challenged adolescents: a group intervention study. PhD thesis submitted to Department of Psychiatric Social Work. NIMHANS, 2011.
4. Publications of National Institute for the Mentally Handicapped, Secunderabad. Available at www.nimhIndia.gov.in/list.htm
5. Welfare benefits for persons with psychiatric disability. Psychiatric Rehabilitation services, Department of Psychiatry, NIMHANS.
6. What after me? Medico pastoral Association; Department of Psychiatry, Bangalore Medical College & Research Institute, and Karnataka State Mental Health Authority. 2011.

Acknowledgement

- Karnataka Parents Association for Mentally Retarded citizens, Bangalore.

*Consult your doctor to know if referral to
Psychiatric Rehabilitation services is suitable for you.*

For more details, contact

PSYCHIATRIC REHABILITATION SERVICES
DPNR building (Opposite State Bank of Mysore), NIMHANS
Email: nimhansrehab@gmail.com
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Who can help parents in understanding and addressing ‘what after me?’ issues?

- Mental Health professionals (Psychiatrists, Clinical Psychologists, Psychiatric Social Workers, Nurses): Mental Health professionals will help evaluate the general intellectual abilities and developmental needs of the persons and ways to develop necessary competencies in the individual. They can help in diagnosis and management of associated medical conditions, handling sensitive issues like sexuality and make appropriate referrals for other, need-based services. If parents can plan and empower their ward with ID so that they are not an emotional or financial burden, others are more likely to take up responsibility of their ward with ID after the parents’ life time.
- Teachers trained in special education can help in providing education and training to the child.
- Vocational instructors can help in vocational training and job placement.
- Depending on the need, parents may have to consult speech therapist, physiotherapist and occupational therapist.
- Parent self-help groups are a useful forum to share views, gain fresh perspectives and support each other. PARIVAAR-National Confederation of Parents’ Organizations (NCPO) is a Federation of Parents Associations and NGO’s in 30 States of India are working for people with intellectual and developmental disabilities (IDD) Such as Mental Retardation, Autism, Cerebral Palsy and Multiple Disabilities. (www.parivaarnfpa.org). PARIVAAR is a grassroots level organization with 112 urban, 60 semi-urban and 50 rural parents associations. Parent caregivers have played an active role in social transformation through advocacy, activism and helping in legislation and policy development, and facilitating services such as respite and residential care.

When does the question ‘What after me?’ arise?

Parents are confronted with this question at any time but more so under the following circumstances:

1. When they become old or retired
2. When they develop medical conditions
3. When their ward has become an adult and there is no one besides the family to support the ward
4. When immediate or extended family members are not willing to take care of the person with ID
5. When pointed out by mental health professionals, relatives, neighbors about the future plan for the ward

Why it is important for parents to address the ‘what after me’ issue?

Parents would like that the care they have taken for their wards is ensured even after their lifetime. They may be particularly interested that the following needs are met on permanent basis:

1. Basic needs such as food, clothing, shelter and safety
2. Emotional/social needs such as affection, recognition, group affiliations, achievement, employment, remuneration, recreation, and leisure
3. Health and rehabilitation needs such as periodic follow-ups with professionals for management of health-related problems and special needs arising out of the condition.

To ensure these needs are met even after the lifetime of the parent, it is important to address the guardianship issues.

Importance of guardianship certificate in ‘What after me?’ issues

Parents are the natural guardians of their children till age 18 years. Often, parents identify a family member (usually a sibling) or a relative and discuss with them about caring for their ward with ID after their lifetime.

After 18 years of age, parents need to apply for legal guardianship for their ward with ID to the district magistrate. The guardianship issues are addressed exclusively under National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999). District Disability Welfare Officer (DDWO) can provide more information in this regard. In some districts, this responsibility is handled by the District Social Welfare Officer. The legal guardian can be more than one individual (a parent, sibling, family member, relative or well-wisher who is willing to take up responsibility of your ward) or an organization. The guardianship certificate will help in ensuring clarity pertaining to legal and financial issues after parents’ life time. The guardianship certificate is needed to open a joint bank account for the person with ID to avail government welfare schemes.

How can parents ensure financial security?

The finances of the family should be analyzed and planned during parents’ lifetime. A certified financial planner can help plan asset allocation and investment so that available resources are optimally utilized for foreseeable future. Parents can also form a Trust or make a Will for taking care of their ward with ID. Kindly refer to our information leaflet on ‘Making a Will/ Forming a Trust’² for more details.

What welfare schemes are available for my ward with ID?

Persons with Disability Act (1995) recognizes Mental retardation (old term for ID) as one among the seven disabling conditions. Welfare benefits are available to both the person with disability and the caregivers. Kindly refer to a pamphlet on ‘Welfare benefits for persons with psychiatric disability’ for more details⁵. To avail welfare benefits, parents need to obtain disability certificate for their ward with ID from a government hospital/ District Disability Welfare Officer [DDWO].

What schemes are available under National Trust Act?

Several schemes are available under National Trust Act (details can be accessed at www.thenationaltrust.co.in). Parents can benefit from various schemes like group insurance scheme and health insurance schemes. *Niramaya* scheme provides health insurance coverage of up to one lakh rupees at a nominal fee for persons with mental retardation, autism, cerebral palsy and multiple disabilities⁵. More details can be accessed from the website www.niramayascheme.com. Persons with ID can also avail *Swavlamban Health insurance scheme* which offers family floater policy of Rs 2 lakhs per annum.

Does marriage provide a solution to ‘what after me?’ issues?

Some parents think that marriage will help their ward with ID have a life companion to take care of their needs. It is important to understand that marriage will not improve the intelligence of the person nor it can guarantee guardianship. If family is considering marriage for their ward with ID, they need to understand whether the person with ID is interested and is in a position to fulfil marital responsibilities.

There are instances of persons with mild ID being happily married with support from spouses and their families. However, there may be problems if the prospective spouse is not informed about person’s condition or is unwilling to accept associated challenges. There could also be other issues such as capacity for sexual functions, reproductive ability, and the risk for the offspring. For further guidance on marriage, families can seek counseling from trained mental health professionals.

Can institutions take care of my ward with ID?

Some parents express a desire that institutions take care of this responsibility. There are few centres which cater to this need. Caregivers may entrust such centres with the responsibility if they are comfortable with the facilities offered and expenses involved. To locate such facilities in your community or in the nearest location,