State Society for Ultra Poor and Social Welfare
Government of Bihar

Guidelines for Operating Standards of Care & Protection for PwDs

Submitted by

Samir Ghosh

Consultant, SSUPSW

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Introduction

The care and protection of Persons with Disabilities (PwDs) must be informed by sensitivity, empathy while being mindful of their rights and dignity. International trends indicate a shift from institution-based care of PwDs to care within families and communities, with continuous State support. The current language, philosophies and service models, emphasize the move towards individualized supports and person-centered service delivery.

The intention of person-centered approach to service is to maximize as reasonably as possible the capacity for PwDs to take control of their lives. Individuals are the centre of service design, planning, delivery and review. They direct service and support arrangements to suit their strengths, needs and goals with support of their families, friends, care-givers and advocates.

Thus the aim of institutionalization should be support PwDs to reach a level of independence and from there on exploring options of independent living, home-based care, community care, group homes. In countries like the USA, State services provide In-home support and assistance in purchasing in-home support so as to promote independent living. In home-based care, training of family members and community involvement must be accompanied by support from State agencies by enabling access to all entitlements as well as trained human resource. Group homes require the full-time presence of trained personnel to look into various aspects of independent living with special emphasis on their safety.

The institutions' role today is to provide long term for very specific individuals with high support needs such as those with intellectual disabilities, mental disabilities and multiple disabilities. The intention of treatment of PwDs with high support needs must be towards increasing autonomy and improved quality of life and not to keep people and their condition 'under control'. PwDs should not be looked at as objects of treatment, but as human beings deserving of respect and dignity and their right to self-determination (*WHO Quality Rights Toolkit)*

The following pages lay down the minimum standards of care for PwDs living in residential institutions and borrow from trends in countries like the United States of America, Ireland

and Australia, with adaptations made to the Indian context, further refined to the state of Bihar. The nature of these institutions could be government, government-aided or private. It would be advisable to maintain these minimum standards while providing residential services for PwDs. In case of institutions which have private managements, appropriate norms may be set for their recognition by government authorities and monitoring by independent agencies.

Provisions in the UNCRPD

Services and facilities for PwDs should be in accordance with Human Rights Principles and in tandem with UNCRPD. Standards of Care for PwDs should adhere to the following entitlements enshrined in the UNCRPD:

1. The right to an adequate standard of living and social protection (Article 28 of the CRPD).
    a. Many people staying in residential facilities have inhuman living conditions, including overcrowding and poor sanitation and hygiene. Residents lack proper clothing, clean water, food, heating, decent bedding and privacy. The social environment is often no better: people are denied the opportunity to communicate with the outside world, their privacy is not respected, they experience excruciating boredom and neglect and little or no intellectual, social, cultural, physical or other form of stimulation.
    b. Article 28 of the CRPD requires, among other things, that people with disabilities are provided with an adequate standard of living, including adequate food, clothing, clean water, devices and other assistance for disabilities and continuous improvement of their living conditions.

2. The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD)
    a. All People with Disabilities must be given the health services they need, as close as possible to their communities. It also requires that they be given the same range, quality and standard of free or affordable healthcare, including sexual and reproductive health, as all other people

3. The right to exercise legal capacity and the right to personal liberty and the security of person (Articles 12 and 14 of the CRPD).

a. People with disabilities, (especially those with mental, intellectual disabilities and multiple disabilities) routinely experience violations of their right to exercise their legal capacity. They are often considered incapable of making decisions about their own lives, and key choices that concern them (e.g. about their place of residence, their medical treatment, their personal and financial affairs) are made by families, carers, guardians or health professionals. Furthermore, people in countries all over the world are given medical treatment or admitted to residential facilities without their express informed consent.
b. Article 12 of the CRPD re-asserts the rights of people with disabilities to exercise their legal capacity on an equal basis with others in all aspects of life. They must therefore remain central to all decisions that affect them, including about their treatment, where they live and their personal and financial matters. Article 12 also states that, when needed, people should be given support in exercising their legal capacity. This means that they should have access to a trusted person or group of people, who can explain issues related to their rights, treatment and other relevant matters and who can help them to interpret and communicate their choices and preferences. The people providing support could include advocates, a personal ombudsperson, community services, personal assistants and peers
c. Article 14 of the CRPD (the right to liberty and security of person) is an important provision in relation to admission without informed consent. It states that people with disabilities must not be deprived of their liberty unlawfully or arbitrarily, that any deprivation of liberty must be in conformity with the law and that the existence of a disability shall in no case justify deprivation of liberty

4. Freedom from torture or cruel, inhuman or degrading treatment or punishment and protection from exploitation, violence and abuse (Articles 15 and 16 of the CRPD)
   a. Article 15 requires that all appropriate measures be taken to prevent people with disabilities from being subjected to torture or cruel, inhuman or degrading treatment or punishment. This Article also states that no one must be subjected to medical or scientific experimentation without his or her free consent. Article 16 requires that all measures be taken to protect people against and prevent all forms of exploitation, violence and abuse. This Article also requires that all appropriate measures be taken to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of people with

disabilities who become victims of any form of exploitation, violence or abuse, including by the provision of protection services. In addition, recovery and reintegration must take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

b. Article 16 requires that all facilities and programmes designed to serve people with disabilities be effectively monitored by independent authorities.

5. The right to live independently and be included in the community (Article 19 of the CRPD)
   a. People with disabilities experience wide-ranging violations and discrimination, which prevent them from living and being included in the community. They are denied opportunities to work and get an education and access to the social and financial support they require to live in the community. They are also restricted in the exercise of their right to vote and to join and participate in political, religious, social and self-help or advocacy organizations. They are unable to exercise their religious or cultural practices and are denied opportunities for leisure, fitness and sports activities.
   b. Article 19 states that people with disabilities have the right to live in the community and that government must take effective, appropriate measures to facilitate their full inclusion and participation in society. It further states that people have the right to decide where and with whom they live; they must not be obliged to live in a particular living arrangement. PwDs must be given access to a range of in-home, residential and other community support services, including the personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community

Standards for PwDs in Residential Institutions

As discussed earlier the aim of residential institutions should be to help individuals reach a certain level of independence which allows them to live in society (with support wherever required). Segregation of PwDs in institutions leads to several issues, some of which are:

1. Increased cost of care
2. Further invisibilization and marginalization of this vulnerable group
3. Negative impact of social diversity leading to an Ill-equipped people which is unable to understand and accept a section of humanity
4. Increased levels of dependence of the disabled and their reduced participation in society

The Standards of Care for PwDs have been divided into six sections with salient points discussed in detail under each. They are in no way exhaustive, but state the minimum requirements of care that must be provided to PwDs in residential institutions.

Individualized Supports and Care

This standard draws from the idea of person-centered approach to services. The experience of this approach is more than just an individualistic approach to support but requires all aspects of service provision to work together for the holistic care (and treatment where necessary) of PwDs. This section holds special relevance for persons belonging to high support groups as their treatment and care-giving often tends to compromise these aspects. Services and care-givers while acting in good faith, often violate individual right to self-determination, which compromises the overall idea of individualized supports and care.

1. **Rights and diversity to be protected and promoted**

   This includes that the individual rights and diversity with respect to their age, gender, religious and political beliefs, sexual orientation, extent of support required and civil and family status. Residents must be informed of their rights, supported in understanding their rights and exercising them.

2. **Enables exercise of agency and choice**

   The services must be respectful of choices made by residents including the right to determine the kind of interventions and treatment as well as the right to discontinue and/ or refuse it.

Exercise of agency also involves participation in political live, including casting their votes and involvement in political activities.

3. **Supports the development of and maintains relationships with family and community**

   Institutions and services must encourage interaction of residents with their families and work towards the aim of reinstating them in society. Regular visits from family and friends must be invited and residents must also be encouraged to step out of the institution with or without support from staff.

   Adults have the right to also choose partners, pursue relationships and enter the institution of marriage. However, marriage and relationships must not be forced on individuals by their families and care-givers as a means of 'treatment' or 'cure', but only in full consent of both individuals in the relationship.

4. **Provides access to information in accessible format**

   All information regarding the process of institutionalization, therapy, treatment, exercise of legal capacities etc. must be provided to individuals in accessible formats of communication.

   Books and other reading material must also be provided in formats accessible to PwDs so as to enhance their knowledge as well as respect their right to recreation.

5. **Participates in decision-making, provides informed consent, access to advocate wherever necessary**

   All individuals in a residential institution as enrolled and administered medical and other treatment after having expressed free and informed consent. The families and care-givers of all such people must be part of this process, with a clear understanding that the institution will work with the individual as well as the family in order to build autonomy of the individual. All decisions must be communicated to the individual at the start of their lives in institution.

   They must also be provided access to legal aid or lawyers in order to exercise their legal rights for example right to draft their will, represent themselves in court proceedings etc.

Effective Services

Effective Services ensure that proper support mechanisms are in place to enable PwDs to lead fulfilling lives. Some pointers towards making services effective are:

1. **Development of holistic Individual Care Plans**

   In order for services to be effective, Individual Care Plans must be drawn up in consultation with PwDs, their families and a multidisciplinary team. This Plan must be in writing and filed for record purposes. It should be in keeping with the health, educational, recreational and psychological needs of each resident. It must also be reviewed regularly based on the progress/change in circumstances for each resident so as to enable him / her to reach her maximum potential in the most supportive manner possible.

2. **Services must be accessible and promote privacy and dignity**

   The institutions infrastructure must be designed so that it is accessible, safe and comfortable for all residents. An access audit must be conducted by an independent and external team at regular intervals so that it may be updated and upgraded according to the latest norms. Adequate space must be provided for storage of personal belongings and must be separate for men, women and children.

   Services must not compromise on PwDs right to dignity and privacy at any cost. This includes right to physical spaces from provision of individual beds/ rooms, clothing, toiletries to having privacy as they go about their ADL. This is especially important for children and adults belonging to high support groups- while they might require help in completing their ADL, it may be provided only where necessary. ADL training must be among top priorities while planning for individuals with high support needs, including enabling their access to assistive devices and infrastructural adaptations so as to respect their dignity and privacy.

3. **Right to service and type of service is determined by fair transparent manner**

   Functional Needs Assessment must be conducted by a competent individual, based on which hours and type of care may be decided. If an individual has basic functional abilities, example independence in ADL, then in-home support may be provided linked to the institution, where a care-giver visits the home for other purposes such as skill development, language and communication and / or educational purposes. The intention must be to encourage PwDs to live in their

homes with their families and encourage community support and minimize institutionalization. For PwDs with high support needs and / or absence of family and community care, residential options are but necessary.

4. **Children and young adults are supported through their transition into adulthood and to adult residential care or independent living**
   While it is crucial that all Individual Care Plans be designed to suit the needs of each child or young adult, the goal must be to enable that child to transition smoothly into adulthood. This would include equipping them with ADL skills, socialization and behavior modifications where necessary. Another crucial aspect of facilitating smooth transitions to adulthood would be educating them about aspects of sexual and reproductive health so as to not only prevent or report instances of violence and abuse, but also enable the exercise of agency in enjoying personal lives and intimate relationships irrespective of their gender or sexual preferences.

Safe Services

Residential services must be planned carefully after due assessment of risks and adverse events. This is especially important in the case of individuals with high support needs, women and children. Where individuals display behavior that may be putting their safety at risk, or threatening to risk that of others therapeutic inputs must be provided. However, it is important to support responsible risk –taking that is appropriate to a person's age and capacity. Other important aspects of safe services involve the following:

1. **Protection from abuse and neglect**
   Staff works in partnership with residents and their families/ care-givers (wherever available) to promote their safety and well-being. Intimate care provided to persons in high support groups is closely monitored.
   Clearly defined procedures must be in place for the resolution of allegations of abuse by staff that prioritizes the safety of the residents and ensures that the persons against whom allegations are made are treated fairly. All details of such procedures and protocol to be followed must be clearly communicated to staff members.

2. **Care that promotes positive behavior and emotional well-being**
   Clearly written policies on behavior support for residents that promotes positive approach to the management of behavior must be in place. Therapeutic inputs must

be provided wherever necessary to strengthen such an approach. Positive approach to behavior support must be tailored to individual needs that is appropriate to age, ability and stage of development in case of children. Socialization of residents is an equally crucial aspect of behavior support.

3. **Limited use of restrictive procedures**

   Residents are not subjected to restrictive procedure unless there is evidence that has been assessed that they are a serious risk to safety of others

   Residential services must limit the use of restrictive procedures and use them only as emergency interventions. All such procedures must be brought to the notice of senior management, and as far as possible, be notified to them in advance. All restrictions imposed on a resident must be included in the individual personal files for the purposes of record keeping.

   Staff in the residential services must be trained in the process of using restrictive procedures and only used approved and agreed techniques. They must also be trained in conciliation and de-escalation to reduce the likelihood of violence and the need for restrictive procedures.

4. **Management of adverse events**

   The residential service must have proper policies and procedures in place for the management and review of adverse events and incidents. All such incidents must also be reported to the relevant health office in accordance with state and national rules and regulations.

   The Service must ensure the effective dissemination of recommendations and learning from the management and review of adverse events and incidents. This means that the learning must be passed on to all staff members and also be used to inform the development of best practices.

Health and Development

Promoting the health and development of individuals is essential for their physical, cognitive and emotional growth. These play a huge role in forming and maintaining bonds with family and the community at large

1. **Regular Health Assessments**

   Health and Development of each resident of the institution must be carefully monitored and promoted through regular assessments. This must be recorded in the individual care plan and competent therapists from the field of mental health, occupational therapy, physiotherapy, speech and language therapy, mobility instructors etc. must be brought in to address the diverse therapeutic needs of all residents. In the case of children, access to early detection and intervention services is critical to the development and well-being of the child.

   In case of unavailability of any of the services crucial to the health of residents, their families must be informed, and the residential service must link with other relevant experts/ service providers or refer the residents to them.

   Special attention must be paid to the nutritional needs of all residents, especially those in high support groups and on medication. Inputs from a pediatrician for children and dietician for adults would be useful in planning for a well-balanced diet for all. Apart from diet, physical activities is of equal importance in maintaining the health of all residents as some conditions coupled with medication tend to accelerate obesity, hypertension, diabetes. Physical activity in sync with age and capacity can prove extremely useful in not only maintaining the physical fitness, but also emotional well-being of residents.

2. **Supportive policies & procedures for medication management in place**

   Some persons including belonging to high support groups often need to be administered or helped with their medication. Adherence to medication need special monitoring in the case of persons with mental illnesses. Staff must be trained to read prescriptions and safely administer all medication, their storage and disposal for all persons needing such support.

   Following a risk assessment, individuals may be allowed to take responsibility for their own medication.

   Medication of every resident must be periodically reviewed, and all information must be recorded in their individual files.

All medication errors, suspected adverse reactions and incidents must be recorded not only in individual files, but also brought to the notice of medical professionals and management of the institution to prevent recurrence and rectify mistakes.

3. **Education, recreation, training and employment opportunities provided to all to promote & maximize individual capacities**

   The residential institution must develop an education and skill development policy, separate for children and adults. The children in the institution should as far as possible be enrolled in a mainstream school. For all the others who cannot go to mainstream schools, should be provided with special educators.

   Residents should have access to skill development programmes which have been designed in congruence with the national skill development policy and other programmes of the NHFDC and the Ministry of Social Justice on financial assistance for skill training of PwDs. The focus of education and skill training must be geared towards enabling financial independence so that PwDs are able to meaningfully contribute to their households or live independently, as the case may be. Ideally, all persons placed for employment must be provided with 'transition training' so as to equip them to cope with the expectations of a 'work atmosphere'. Persons belonging to high support groups may be linked with sheltered workshops to enable them to work and earn with dignity while simultaneously ensuring their safety.

   Comprehensive records must be maintained of each resident's educational history, educational inputs and skill training provided. The address of employers must be kept so as to support both residents as well as their employers.

Leadership, Governance & Management

This is an important aspect governing standards of care and protection for PwDs. Institutions providing care to such persons must do so in accordance with the Persons with Disabilities Act, 1995, the UNCRPD and the Bihar State Policy for Empowerment of Persons with Disabilities. The institution should have effective management with clear accountability structures and an unbiased and transparent grievance redress mechanism in place. The senior management will make efforts to train the next line of managers so as to decentralize planning and management wherever possible.

For government and government aided institutions, suo moto disclosure of information under Section 4 of the Right to Information Act shall be made, with a designated Public Information Officer. The institution policies shall clearly state that equal services shall be provided to all, irrespective of caste, class, gender and sexual orientation.

All services sourced from external agencies shall be made effective through written undertakings / MoUs and monitored through independent external agencies. There must be an internal management structure appropriate to the size, purpose and function of the institution, with effective management skills demonstrated by a team that is dedicated to the continuous improvement of the institutions and residents. Strategic and operational plans of the institution must set clear objectives and plans for the delivery of person centered, safe and effective services.

A robust internal monitoring mechanism must be built and external evaluations must be conducted at periodic intervals to ensure that the institution is in the direction of the strategies and objectives laid down. Regular financial audits of the residential institutions shall be conducted to maintain credibility and accountability in financial transactions. Organizational policies and standards of care must be reviewed every 5 years so as to keep up with standards of services provided internationally.

Responsive Work Force

A clear recruitment policy can contribute immensely to a responsive workforce. Staff members employed would demonstrate not only skills required to work on various aspects of disability but also show personal attributes such as sensitivity, empathy and integrity. The recruitment process should be independent of person's gender, caste, sexual orientation, abilities and health status. A clear institutional policy in lines with the Vishakha judgment to prevent sexual harassment of women in workplaces must be put in place. Each staff member should be provided with a written job description, copy of terms and conditions of employment and code of conduct prior to joining. Newly recruited staff members are provided with orientation and induction training before they start working at the residential service. An individual personnel file must be maintained for all staff.

The institution should be equipped with in-house as well as external resource persons to support staff members and provide opportunities for professional growth. Investing in capacity building of staff members would directly lead to improved outcomes in residents.

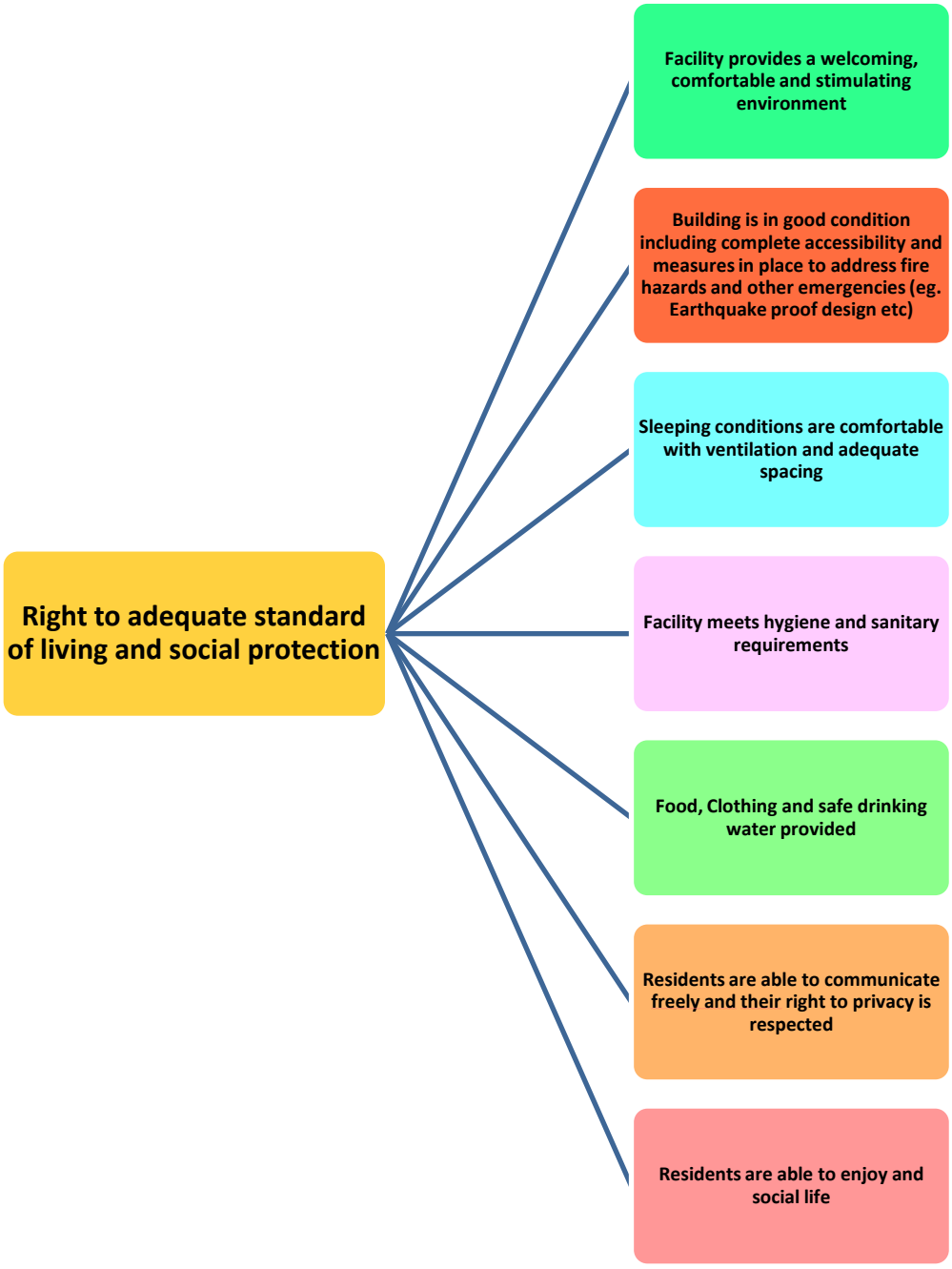
Regular internal feedback mechanisms and performance appraisals must be conducted to keep staff motivated. At all times, there is sufficient number of staff present to look into the needs of all residents. This includes a higher staff to resident ratio for those in high support groups.

Use of Information

A robust and secure management information system for record-keeping must be developed to support the delivery of person-centered and effective services with regular updates on progress made by residents in response to their respective individual care plans. Information is collated, managed and shared to support effective decision-making in compliance with state and national legislations mentioned earlier. All personal information of residents gathered for purposes of MIS is done so with informed consent and full disclosure to families of residents wherever possible.

All information and records for government and government aided services to be accessible to public as per entitlements within the Right to Information Act, 2005

Standards of Care for PwDs (Adapted from WHO Quality Rights Toolkit for mental health)



Glossary of Terms

Abuse: Any act, or failure to act, which results in a breach of a vulnerable person's human rights, civil liberties, physical and mental integrity, dignity or general wellbeing, whether intended or through negligence, including sexual relationships or financial transactions to which the person does not or cannot validly consent, or which are deliberately exploitative. Abuse may take a variety of forms:

- physical abuse, including corporal punishment, incarceration (including being locked in one's home or not allowed out) over- or misuse of medication, medical experimentation or involvement in invasive research without consent, and unlawful detention of psychiatric patients;
- sexual abuse and exploitation, including rape, sexual aggression, indecent assault, indecent exposure, forced involvement in pornography and prostitution;
- psychological threats and harm, usually consisting of verbal abuse, constraints, isolation, rejection, intimidation, harassment, humiliation or threats of punishment or abandonment, emotional blackmail, arbitrariness, denial of adult status and infantilising people with disabilities, and the denial of individuality, sexuality, education and training, leisure and sport;
- interventions which violate the integrity of the person, including certain educational, therapeutic and behavioural programmes;
- financial abuse including fraud and theft of personal belongings, money or property;
- neglect, abandonment and deprivation, whether physical or emotional, in particular an often cumulative lack of healthcare or negligent risk taking, of food or of other daily necessities, including in the context of educational or behavioural programmes;
- institutional violence with regard to the place, the level of hygiene, the space, the rigidity of the system, the programme, the visits, the holidays.

Accessible Format: the presentation of print and online information in plain English/Hindi/other vernacular language, in a manner suited to adults and children with disabilities, including large print, audio and Braille.

Adverse Event: an incident which results in physical and/or emotional harm to a resident.
Autonomy: the perceived ability to control, cope with and make personal decisions about how one lives on a day-to-day basis, according to one's own preferences.

Capacity: capacity means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made. A person lacks the capacity to make a decision if he or she is unable to understand the information relevant to the decision, unable to retain that information, unable to use or weigh that information as part of the process of making the decision, or unable to communicate his or her decision

Child: a person under the age of 18 years

Competency: the behavioural definition of the knowledge, skills, values and personal qualities that underlie the adequate performance of professional activities.

Fit Person: For the purposes of these standards, being a fit person means that the registered provider has the skills, knowledge and good character to safely and effectively provide services to people residing in designated centres

Neglect: This is defined as a type of maltreatment related to the failure to provide needed, age-appropriate care. Unlike physical and sexual abuse, neglect is usually typified by an ongoing pattern of inadequate care and is readily observed by individuals in close contact with the child or person.

Person belonging to High Support Group: Persons with mental disabilities, intellectual disabilities and / or multiple disabilities

Person with Disability: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others

Quality: quality is meeting the assessed needs and expectations by ensuring the provision of efficient and effective management and processes

Record: a record includes any memorandum, book, plan, map, drawing, diagram, pictorial or graphic work or other document, any photograph, film or recording (whether of sound or images or both), any form in which data are held, any other form (including machine-

readable form) or thing in which information is held or stored manually, mechanically or electronically and anything that is a part or a copy, in any form, of any of the foregoing or is a combination of two or more of the foregoing

Restrictive Procedures: a restrictive procedure is a practice that limits an individual's movement, activity of function; interferes with an individual's ability to acquire positive reinforcement; results in the loss of objects or activities that an individual values; or requires an individual to engage in a behavior that the individual would not engage in given freedom of choice. Restrictive procedures include physical or chemical restraint or single separation.