

# Providing Statutory Information

Disability is not only a medical issue but also has significant implications for society. In most countries, there are government schemes to provide the reasonable and necessary supports required by eligible participants to live an ordinary life and to participate in the social and economic life of the community. While the health systems of most countries have integrated the care of people with disabilities, the way the programs are organised vary across different parts of the world.

Healthcare practitioners will need to be aware of their own local and national schemes and have a responsibility to provide information to such support schemes (with consent), by describing the functional impact of the person's disability.

Examples are provided of how support is provided in a developed country (Australia) and a developing nation (India).

## Healthcare practitioners will be approached by people with CP and their families for:

- Documentation confirming:
  - the cause of the disability (if known);
  - the way the disability impacts on daily life and function; and
  - whether their need for support is likely to increase, decrease or stay the same over time (prognosis).

This information can be used to determine eligibility for the government schemes and to inform the development of the person's goals, support needs and associated funding. In certain situations and systems, access to resources may be based on diagnosis rather than functional ability. It is important to provide information on both diagnosis and functional ability to ensure that all appropriate sources of support can be accessed.

## The Australian system is called the National Disability Insurance Scheme (NDIS)

To become an NDIS participant a person must:

- Have a permanent disability that significantly affects their ability to take part in everyday activities, or have a developmental delay.
- Be aged less than 65 years when they first apply to enter the NDIS.
- Be an Australian citizen or hold a permanent visa or a Protected Special Category visa.
- Live in a part of Australia where the NDIS is available.

The NDIS can also be accessed for early intervention. A specific Early Childhood Early Intervention approach has been developed by the NDIS for children aged 0 to six years.

The NDIS involves having a planning conversation with a coordinator who assists in developing a plan with the person with a disability and / or their families. The NDIS aims to build on and support, rather than replace, current informal and mainstream supports. The NDIS focuses on both short-term (12 months) and long-term (1– 5 years) goals that are priorities for the person, and the necessary supports required to meet these goals.

Government support schemes vary between different countries — be aware of the scheme in your own location



These resources are designed to support healthcare practitioners in the care of their patients with cerebral palsy in Australia. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. They have been amended for use by healthcare workers globally in partnership with IAACD. The initial project was funded by an Avant Quality Improvement Grant 2017.

### The Indian support system is called the Niramaya Scheme

The Niramaya Scheme seeks to provide financial support to persons with disabilities including cerebral palsy. The Scheme is available across the country and is managed by the National Trust, which is under the direction of the Ministry of Social Justice and Empowerment.

Disability Rehabilitation Centres are an initiative of this Ministry, to facilitate comprehensive services to persons with disabilities in rural areas. These units have teams of professionals providing services including identification of disability, early detection and intervention, provision and repair of assistive devices, therapy services including physiotherapy and speech pathology and they also facilitate provision of disability certificates, and other concessions.

District Early Intervention Centres are under the Rashtriya Bal Swasthya Karyakram which is the national health program for children in India addressing birth defects, diseases, and young people with developmental delays or disabilities. Children with cerebral palsy are provided with integrated services from birth until school entry using a multidisciplinary approach. .

Government schemes are often not primarily interested in the medical diagnosis but rather on how that diagnosis impacts on a person's function and consequent need for support. Support may involve another person, or it may involve aids and equipment, and is considered in relation to different life domains.



### Describing functional impact of disability

The various government schemes are not primarily interested in the person's medical diagnosis, but rather how that diagnosis impacts on that individual's function and consequent need for support. Support may involve another person, or it may involve aids and equipment, and is considered in relation to these eight life domains:

- **Choice and control:** Understand, make and express decisions about preferences, priorities, experiences and life directions.
- **Education:** Engage in educational activities to build knowledge and skill. Ability to understand, learn and remember new things.
- **Health and wellbeing:** Self monitor health, identify illness, seek appropriate advice from the right health professional, organise and attend appointments, implement management recommendations.
- **Employment:** Engage in voluntary or paid employment with or without support.
- **Relationships:** Maintain and build relationships with family members and friends; form and evaluate new relationships; cope with and regulate feelings and emotions; keep safe and respect the rights and choice of others.
- **Social and community activities:** Participate in social and community life. Community activities of daily life include transport, money handling, budgeting and shopping.
- **Home and living situation:** Live in an appropriate setting with required support.
- **Daily activities:** Organise and attend to personal activities of daily living including bathing, dressing, eating and drinking.