### System functions

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<tr>
<th>Governance</th>
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  • Improving access to health care among people with disabilities in Uruguay  
  • National Roadmap for Improving the Health of People with Intellectual Disability in Australia | • COVID-19 Disability Advisory Group (CDAG) in Canada  
  • Advisory Committee for the COVID-19 Response for People with Disability in Australia | • Dental health reimbursement for people with disabilities in Germany  
  • National Disability Insurance Scheme in Australia  
  • Coverage of disability-related services for children with disabilities in The Philippines | • Learning Disabilities Mortality Review (LeDeR) programme in the UK  
  • Learning Disability Registers in the UK |
### Autonomy and Awareness
- Active Rehabilitation Services by and for people with disabilities in Poland
- Peer educator training on sexual and reproductive health and rights of people with disabilities in Burundi
- Autism and Mental Health Literacy Project (AM-HeLP) in Canada

### Affordability
- Accessible COVID-19 Vaccination Transportation in Toronto, Canada

### Human Resources
- Community Health Worker Training in India
- Disability-inclusive Nursing Practice Handbook in Germany
- Eye care capacity building in low- and middle-income countries
- Learning Disability and Autism Training for Health and Care Staff in the UK
- Health worker handbook on sexual and reproductive health in Ecuador
- Disability and inclusion training for health care workers in Tanzania
- Future Learn: Improving Health Assessments for People with Intellectual Disabilities
- Disability Training for Community Health Assistants in Zambia

### Health Facilities
- Home Testing for COVID-19 in the United Arab Emirates

### Specialized Services & AT
- Annual Health Checks for people with learning disabilities in the UK
- Wheelchair user training in El Salvador, India, Kenya, Nicaragua, and Romania
- Comprehensive community-based rehabilitation in Tanzania
- National Rehabilitation Plan in Ukraine
## National Clinical Programme for People with Disability

### Best practice description

Housed within the Ministry of Health, the National Clinical Programme for People with Disability (NCPPD) seeks to support the provision of effective and efficient health and social care for people with disabilities. Created in March 2020 and composed of three members and a number of associated Disability Specialists, the programme aims to design clinical services that are evidence-informed, context-appropriate, and based in the social and rights model of disability. The NCPPD is advised by the Disability Advisory Group (DAG), consisting of 20 members drawn from each of the nine disciplines which each have a unidisciplinary sub-committee, a range of disability-stakeholders (e.g., service users, carers, associations, service providers, etc.) and representatives of the National Disability Operations and Strategy and Planning programmes. The NCPPD also works closely with other specialized clinical programmes such as mental health, rehabilitation, older persons, etc.

### Origin / impetus for best practice

- Ireland’s ratification of the United Nations Convention on the Rights of Persons with Disability in 2018 committed it to the inclusion of people with disability in decision making structures.
- Increasing recognition that governance structures dominated by a single profession are sub-optimal for designing integrated clinical services.
- Existing commitment to enhancing the role of other professions through the Health and Social Care Professions Office.
- Promotion by NCPPD personnel of equity of esteem, interdisciplinarity and co-leadership across professions.
- Opportunity to rapidly progress establishment of the new NCPPD due to the exigencies of Covid-19 pandemic.

### Impact / results of implementing best practice

- Development of suite of national guidance documents to support health and social care delivery during the COVID-19 pandemic resulting in lower morbidity and mortality by international comparison.
- Supporting health workers training to adapt disability assessments and interventions during COVID-19, thereby ensuring continuity of safe and essential services.
- A survey on digital and assistive technology for disability services recognized good practice and scalable projects for acceptable and safe services, supports and opportunities beyond COVID-19 pandemic.
- Changing expectations of people with disability and health and social care professions through co-design, parity of input and integrated approach.

### Impact statement

“The NCPPD has bridged the gap between social care and healthcare in Ireland. The programme has created a fit-for-purpose governance structure which will ensure that integrated health and social care services are co-designed with people with disability, civil society, clinical and care practitioners; is rights-based, and determined by person and family-centered needs.”

- NCPPD team

### Critical success factors for best practice

- Leveraging ratification of UNCRPD
- Political and clinical window of opportunity for disability related agenda-setting
- People with disabilities and/or their representatives are centred in the programme
- Strong backing from health and social care leadership

### Lessons learned

- The relevance of the UNCRPD to clinical contexts has to be claimed and demonstrated.
- The principle of participation has to be embedded for service providers as well as service users.
- Conventional practices need to be challenged by credible people with credible alternatives.
- Senior allies open to change must be identified and engaged.

### Sources

1. National Clinical Programme for People with Disability
2. NCPPD Programme Governance
3. The Impact of COVID-19 on People with Disabilities
4. COVID-19 posters and resources
5. COVID-19 HSE Clinical Guidance and Evidence

### Further links & information

- Guidance on Conducting Assessments in Disability Services
- Survey on Digital and Assistive Technology use in Disability Services

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Date: March 2021
Improving access to health care among people with disabilities in Uruguay

**Best practice description**

In 2018, the project ‘Right to equality and non-discrimination of persons with disabilities’ was launched in Uruguay to improve access to health care among people with disabilities. Based on a human rights framework, people with disabilities, institutional actors and civil society established the minimum requirements to guarantee access to health care:

1. Health service providers use the Washington Group’s set of questions to identify people with disabilities.
2. Health care workers are trained about disability-inclusive health care with a human rights approach.
3. Each health facility has a focal person that provides all disability-related information.
4. Inclusive health care facilities and services are widely advertised in the population.
5. Diverse communication and information supports (e.g. braille, sign language interpreters, etc.).
6. Wait-times and appointments lengths are altered according to specific needs.
7. Direct and indirect disability-related costs are supported.
8. Universal design of health facilities.

**Origin / impetus for best practice**

- In 2016, an investigation found multiple forms of discrimination in Uruguay. This led the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination against Women of Uruguay to call on the state to guarantee the rights to equality and non-discrimination of people with disabilities.

**Impact / results of implementing best practice**

- Training of 300 health care workers in different regions of the country and in both public and private health providers.
- Training of 50 institutions on the Washington Group questions to systematise data on disability.
- Production of accessible free online sexual and reproductive health resources.

**Critical success factors for best practice**

- Funding by the United Nations Partnership on the Rights of Persons with Disabilities Multi Partner Trust Fund.
- Direct participation of people with disabilities.
- Intersectoral approach including civil society and institutional actors.

**Impact statement**

- 

**Lessons learned**

- Permanent collaboration between actors from different institutions improves the quality of products.
- The participation of people with disabilities in the design, elaboration and validation of products is essential.
- Involvement of people with disabilities is key during training, agreement and negotiation processes.
- The shift towards a social and human rights model of disability is a gradual process.

**Sources**

- Official project’s website
- Minimum requirements to guarantee health care access among people with disabilities [in Spanish]
- Accessible resources about sexual and reproductive health [in Spanish]

**Further links & information**


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**Geography and scale:** Uruguay; National

**Type of disability:** All types of disabilities

**Involved actors:**
- Ministry of Health
- Ministry of Social Development
- PAHO/WHO
- OPDs
- UN Women
- UNPF

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‘Right to equality and non-discrimination of persons with disabilities’

Click on the image to visit the official website, all information in Spanish.
National Roadmap for Improving the Health of People with Intellectual Disability in Australia

Geography and scale: Australia; national

Type of disability: People with intellectual disability

Involved actors:
- Australian Government Department of Health
- People with intellectual disability, family members and carers
- Advocacy organisations
- Clinical and academic experts
- Disability service provider organisations
- Additional Commonwealth agencies and state and territory governments

Best practice description

The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) was launched in August 2021 after an extensive consultation process. The Roadmap is a landmark document that sets out a comprehensive range of actions to improve the health of people with intellectual disability. Key objectives include:

1. Improve support for people with intellectual disability, their families and carers (e.g., health literacy resources, disability liaison officers in health services).
2. Develop better models of care that are person-centred, trauma-informed, and with reasonable adjustments (e.g., toolkits, best practice guidelines and clinical standards).
3. Provide support for health professionals, including training to provide quality, appropriate and disability informed health care.
4. Improve oral health by integrating it into general health care and by promoting access to existing dental services.
5. Strengthen research, data and measurement of health outcomes.
6. Improve emergency preparedness and response to meet the needs of people with intellectual disability.

Origin / impetus for best practice

- Around 450,000 people have intellectual disability in Australia (1.8% of the Australian population).
- Compared to the general population, Australians with intellectual disability have higher rates of avoidable deaths, hospitalisations and health conditions.
- In 2019, the Australian Council for Intellectual Disability, in collaboration with Inclusion Australia, launched the “Our Health Counts” campaign to end deadly disability discrimination across Australia.
- A Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established in April 2019 in response to widespread concern from the community.
- The Roadmap was approved by the Australian Government Minister for Health and Aged Care, the Hon. Greg Hunt MP, in July 2021.

Impact / results of implementing best practice

- Establishing the RIGG and its sub-committees (Intellectual Disability Focus Group, Education and Training Expert Advisory Group, and National Centre of Excellence Expert Advisory Group) to oversee projects.
- To date, $19.26 million in Australian Government funding:
  - $6.6 million to develop a Primary Care Enhancement Program for people with intellectual disability
  - $6.7 million to improve the uptake and implementation of Annual Health Assessments
  - $4.7 million for curriculum development in intellectual disability health, and
  - $1.4 million to scope and co-design a National Centre of Excellence in Intellectual Disability Health.

Critical success factors for best practice

- Including people with lived experience of intellectual disability when developing and implementing the Roadmap.
- Use of best available evidence to highlight the need to take action.
- Powerful disability advocacy and strong political commitment.
- Cooperation and commitment from a wide range of actors, including Commonwealth and state and territory governments, private and not-for-profit providers, universities and health professional bodies.

Impact statement

The Roadmap aims to address serious health inequities faced by people with intellectual disability. It outlines how Australia can create a health system where people with intellectual disability are valued, respected and have access to high quality, timely and comprehensive health care.

Lessons learned

- Robust governance arrangements need to be established early and sustained.
- Meetings need to be accessible for people with intellectual disability (providing materials in Easy Read, asking presenters to speak slowly, and offering pre-meeting briefing).
- Progress reports and communiques are made publicly available to ensure all parties are held accountable for action.
- Strong advocacy from disability and health organisations is needed to ensure continued implementation and funding of projects.

Sources
- National Roadmap for Improving the Health of People with Intellectual Disability
- Roadmap Implementation Governance Group (RIGG)
- RIGG Meeting communiques

Further links & information
- Commit to the National Roadmap for action! End Deadly Disability Discrimination
- The road to the Roadmap – Council for Intellectual Disability
- How will the Roadmap help people with intellectual disability – video

Date: May 2022
Recognizing the profound impact the COVID-19 pandemic has had on persons with disabilities, the Government of Canada created a COVID-19 Disability Advisory Group (CDAG). The Advisory Group is made up of persons with disabilities, allies, academics, and leaders of civil society organizations who work on disability rights and empowerment. Housed within the Ministry of Employment and Social Development, the CDAG meets bi-monthly to advise the Minister, Carla Qualtrough, on the specific issues persons with disabilities are facing during the pandemic. Members of the CDAG have formed several informal working groups who also meet regularly to discuss how persons with disabilities can be included in their respective pandemic response activities and report back to the broader CDAG, the Minister, and other Ministers across the Government of Canada when appropriate. Overall, this machinery has helped to make Canada’s COVID-19 response more inclusive to persons with disabilities.

**Best practice description**

**Title:** Canadian COVID-19 Disability Advisory Group (CDAG)

**Geography and scale:** National; across Canada

**Type of disability:** All types of impairments

**Involved actors**
- Minister of Employment, Workforce Development and Disability Inclusion
- Employment and Social Development Canada
- Health Canada
- Senior Government of Canada Officials and other Ministers
- Disability advocacy groups
- Committee Members (persons with disabilities, allies, academics, and CSO leaders)

**Impact / results of implementing best practice**

- Specific guidelines on disability considerations for the COVID-19 pandemic
- Inclusive and disability-informed triage protocols
- Communication guidelines for inclusive information dissemination

**Origin / impetus for best**

- Government of Canada’s commitment to diversity and inclusion, and its appointment of a Minister responsible for persons with disabilities
- Minister Qualtrough’s personal experiences with disability, and lifelong advocacy work on disability issues, informed need for representation of persons with disabilities in pandemic response.
- Disability community aligned behind key principles for an inclusive pandemic response, which provided room to create a committee.
- The implementation of the Accessible Canada Act (2019) has raised awareness of issues facing persons with disabilities, meaning that other ministries are aware that the “nothing about us, without us” approach to policymaking.

**Critical success factors for best practice**

- Whole of government approach and collaboration
- Representation of persons with disabilities in parliament (i.e. Minister Qualtrough)
- Political will for collaboration and senior leadership drive
- Strong disability community advocacy
- Diverse and intersectional representation of the disability community, particularly Indigenous groups

**Impact statement**

“We know Canadians with disabilities have been disproportionately affected by COVID-19, and are at greater risk due to health, economic, and social conditions. This is why it was essential for the federal Government to get expert advice on the lived experiences of persons with disabilities in real-time. The COVID-19 Disability Advisory Group provided valuable advice and greatly contributed to ensuring our pandemic response was inclusive from the start. I am grateful for their views and commitment.” – The Honourable Carla Qualtrough, Minister of Employment, Workforce Development, and Disability Inclusion

**Lessons learned**

- Jurisdictional challenges prevent full implementation of guidelines, as health is a provincial/territorial issue in Canada and similar structures were not always implemented on these levels.
- Cross-cutting approach to emergency response allowed for greater representation of persons with disabilities.

**Sources**


**Further links & information**

- COVID-19 and people with disabilities in Canada
- Background on Members of the COVID-19 Disability Advisory Group
## Advisory Committee for the COVID-19 Response for People with Disability in Australia

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>Involved actors</th>
</tr>
</thead>
</table>
| Australia: national | • People with disability, family members and carers  
|                     | • Disability organisations  
|                     | • Disability service sector  
|                     | • Research sector  
|                     | • Health care sector (medical practitioners, allied health professionals and nursing)  
|                     | • Australian Government officials  
|                     | • State and territory government officials |

### Best practice description

The Advisory Committee for the COVID-19 Response for People with Disability (Advisory Committee) was established in April 2020 to inform the Australian Government’s response to COVID-19 for people with disability. The Advisory Committee includes people with disability, parents and carers, Australian Government officials, state and territory government officials, experts from the health and research sectors, and major disability advocacy groups. Their role is to provide expert advice on the health care needs of people with disability, their families and the disability service sector, including access to COVID-19 screening, prevention and health care.

The Advisory Committee reports to Australia’s Chief Medical Officer and regularly informs the Australian Health Protection Principal Committee and Communicable Diseases Network Australia. The Advisory Committee meets regularly (fortnightly in April 2022), and oversees implementation of the Management and Operational Plan for People with Disability under the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19). Each meeting begins with people with lived experience sharing any relevant updates to the committee for discussion or further action.

### Origin / impetus for best practice

- The Australian Government recognised that many people with disability were at greater risk of contracting SARS-CoV-2 and adverse outcomes of COVID-19.
- The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability called on Australian governments to take all necessary measures to ensure protection and safety of people with disability during the pandemic.
- In line with its commitment to ensure that people with disability have equitable access to health care, the Government took early action between March and April 2020 to develop a targeted COVID-19 response plan for people with disability, including the formation of the Advisory Committee.

### Impact / results of implementing best practice

- Developed one of the world’s first dedicated plans focusing on people with disability.
- Prioritising people with disability in residential settings during vaccine roll-out.
- Among National Disability Insurance Scheme beneficiaries, 87.7% of those aged 16 and over are fully vaccinated as at 14 April 2022.
- Recognition of people with disability within Australia’s Primary Health Care 10 Year Plan 2022-2032 (launched 25 March 2022).

### Critical success factors for best practice

- Powerful disability community advocacy.
- Government officials commitment to considering lived experience of disability in decision-making processes.
- Strong inter-agency collaboration.
- Cooperation across Commonwealth and state and territory governments.

### Impact statement

The Australian Government, government agencies, and state and territory governments are working together to coordinate an evidence-based response to a respiratory illness outbreak caused by a novel (new) coronavirus (COVID-19).

### Lessons learned

- Importance of disability representatives sharing their lived experience during committee meetings has personalised the challenges and spurred action.
- The need to consider people with disability proactively in health emergency preparedness plans, rather than reactively in response.
- The Advisory Committee has helped enable cross-agency collaboration, which is critical for effective emergency responses.
- Dedicated team needed to do liaison and ensure collaboration within and across governments.
- Publish meeting communiques online to ensure governments are accountable.

### Sources

- Advisory Committee for the COVID-19 response for People with Disability
- Management and Operational Plan for People with Disability
- Advisory Committee meeting communiques
- Australian COVID-19 vaccination daily rollout update

### Further links & information

- The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability
- CDNA national guidelines for the prevention and management of COVID-19 outbreaks in disability residential services • The Disability Supplement
- Australia’s Primary Health Care 10 Year Plan 2022-2032
### Health insurance reimbursement for oral health and dental care for people with disabilities

#### Best practice description

Special regulations apply for people with disabilities already since 2012; simple dental care procedures provided at home and travel costs to outpatient dental facilities covered for persons with severe disabilities. However, in 2018, a new directive was established to further change the reimbursement for insured persons with disabilities. Four main benefits apply: (1) Oral health status assessed and registered on a form with an accessible format; (2) dental calculus removal available and offered; (3) individual oral health plans developed with measures and means to promote dental care and (4) oral health education tailored to the specific needs of each person. For instance with demonstrations and practical instructions. Carers are considered in oral health education and individual health plans when needed. All benefits are provided every six months (once per year for the general population).

#### Origin / impetus for best practice

- Scientific studies had shown that some adults with disabilities have worse oral health (more decayed and missing teeth) than the general population.\(^1^,2^,3\). Main reasons are financial barriers, physical inaccessibility, and lack of knowledgeable health workers.
- The social law stipulates that health insurances need to consider specific needs. Advocates used that to convene stakeholders and develop the “Oral health for elderly and people with disabilities” report, published in 2010.
- Advocates used this report to enforce the new 2018 directive that changed the reimbursement.

#### Impact / results of implementing best practice

- Further regulations are being discussed e.g., life-long fluoridation, additional time for dental treatments, in-patient dental treatments, interventions with general anesthesia.

#### Critical success factors for best practice

- Advocacy (e.g., Special Olympics outreach activities)
- Data collection and evidence building.
- Collaboration among stakeholders.
- Reimbursement of dental services.

#### Impact statement

“...After decades of struggling to improve dental and oral health for patients who still belong to the high-risk group for caries and periodontal disease, this is a great success. For the beneficiaries themselves, but also for the dentists, who have often carried out preventive measures for their patients free of charge”. Dr. med. Imke Kaschke MPH (Head of Health, Special Olympics Germany, 2nd chairperson of AG ZMB).

#### Lessons learned

- Evidence-based data is essential to successfully implement further requirements.
- Training of health workers is necessary, and this may expand the number of actors involved in the field.

#### Sources

Best practice description

Since July 2016, the National Disability insurance Scheme (NDIS) has provided individualized support to people with disability, their families and carers. The main objectives are to support the independence, autonomy, and social and economic participation of people with disability, and to provide reasonable, necessary, high quality and innovative supports, that are chosen and planned by people with disability. The program will provide support for education, employment, social participation, independence, living arrangements and health and wellbeing. Disability-related health support cover for instance: continence, diabetic management, dysphagia, epilepsy, nutrition, podiatry, respiratory and wound and pressure care supports. To be eligible, individuals must:

1. Reside in Australia, be an Australian citizen, permanent resident or Protected Special Category Visa holder
2. Meet the disability or early intervention requirements
3. Be under 65 years of age when the access request is made

Impact / results of implementing best practice

- Under full implementation, the NDIS is expected to cover 500,000 Australians by 2023.

Impact statement

...
**Best practice description**

PhilHealth provides benefit packages covering children below 18 years with developmental disabilities, mobility impairments, visual disabilities, and hearing impairments in The Philippines. These packages include various interventions, ranging from:

1. Assessments by medical specialists
2. Assessments by allied health specialists
3. Rehabilitation therapy
4. Assistive devices (prosthesis, orthosis, spinal bracing, seating devices, wheelchairs, hearing aids, optical aids, electric aid and white cane); including yearly services and replacement of devices.

Currently, these services are provided by a few government health care institutions in the country.

**Origin / impetus for best practice**

- Around five million children have disabilities in the Philippines and only 5% have access to assistive technology.
- Households caring for children with disabilities face a triple financial burden. These are additional costs of accessing general health services, disability specific goods and services, and limited employment opportunities.
- In 2015, PhilHealth began financing packages for adult persons with disabilities. Benefit packages cover assistive devices such as upper and lower limb prosthesis, lower limb orthosis and spinal orthosis, and rehabilitation sessions in four government facilities and three private facilities.
- The Philippines has undertaken a series of reforms since 2019 towards the realization of universal health coverage for people with disabilities, most recently extending it to children with disabilities.

**Impact / results of implementing best practice**

- Other government and private institutions will be contracted to increase availability of assessments.

**Impact statement**

“We are introducing this Z benefit package which is an improved, rationalized and relevant benefit for children with disabilities mainly to prevent the catastrophic spending of the poor and marginalized who are enrolled in the National Health Insurance Program (NHIP) while ensuring quality healthcare services.

Dr. Celestina Ma. Jude P. de la Serna, Interim/OIC, PhilHealth President and CEO (March 2nd, 2018).

**Critical success factors for best practice**

- Country commitment with Universal Health Care
- Increasing the budget allocation for the National Health Insurance Program
- Increased tax on alcohol and tobacco as a source of funding

**Lessons learned**

- This program is expected to trigger supply-side investments by the private sector and local government. In addition to reforms in health professional education to respond to the health human resource gap, with the leadership of the ministries of health and education.

**Sources**

- PhilHealth Benefits package
- RA 11228 – An Act Providing For The Mandatory PhilHealth Coverage For All Persons With Disability (PWDs)
- Implementing rules and regulations of RA 11228

**Further links & information**

- PhilHealth website
Learning Disabilities Mortality Review (LeDeR)

**Best practice description**
Established in 2015, the LeDeR programme is a novel program to help reduce premature mortality and health inequalities among people with learning disabilities, as well as to improve the quality of health and social care delivery. Its key components are:

- Every person with learning disabilities who dies has a local review of their case notes and cause of mortality to write a report. The report reviews potentially modifiable factors of their death, such as the level of care received, involving other agencies to contribute to the investigation whenever necessary.
- All local reviews are submitted to the programme and analysed at a national level. Reports include main causes of death and good practices, which are compiled into an annual report with recommendations. This report is also translated into an easy to read format.

**Origin / impetus for best practice**
- Mencap’s report, Death by indifference, 2007, described cases of institutional discrimination and avoidable deaths of persons with learning disabilities, and called for an urgent independent inquiry.
- The Michael report (2008) revealed that people with learning disabilities had higher levels of unmet needs, received less effective care and had higher risks of avoidable deaths than the general population.
- Findings of the Confidential Inquiry (2013) showed that avoidable deaths of people with learning disabilities were related to quality of care and service provision. Recommendations included the review of deaths, routine collection of mortality data, and the establishment of a national review board.
- See related good practice description in our compendium: Learning Disability Registries.

**Impact / results of implementing best practice**
The findings from the annual reports have led already to significant changes in practice:
- NHS England set out a long term plan to implement national learning disability improvement standards.
- Health and care staff will receive learning disability and autism training.
- Health system changes in local areas are analysed and shared in action from learning reports.

**Impact statement**
"The disparity between people with learning disabilities and the general population in relation to average age at death, causes of death, and avoidable causes of death remains substantial and urgent action is needed."
Professor Pauline Heslop; LeDeR Programme Lead. 16th July 2020 on this link.

**Critical success factors for best practice**
- Mencap’s initial data on early deaths.
- Strong advocacy from the learning disability community.
- Political will for collaboration.
- Dedicated funding from NHS England.

**Lessons learned**
- Reviews have to be high quality and completed in a timely fashion.
- Reviews are not mandatory and reporting rates vary by area; commitment to implementation should be strengthened.
- Mortality trends (cause, geographic location, etc.) can be used to inform policy and research.

**Sources**
- Mencap’s report 2007
- Healthcare for all, Michael Report 2008
- Confidential Inquiry 2013

**Further links & information**
- LeDeR programme - University of Bristol
- Action from learning - NHS
- Learning disability improvement standards
# Learning Disability Registers

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>England, national.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of disability:</td>
<td>People with learning disabilities of all ages</td>
</tr>
</tbody>
</table>

## Best practice description
In order to reduce health inequalities and improve primary care, learning disability registers were established in 2006 and now cover nearly 285,000 patients. People with learning disabilities are identified and diagnosed by general practitioners (GPs) and then included in a register. This information is coded and added to the patients’ electronic health records. In addition, persons with coded clinical diagnoses associated with a learning disability are automatically added to the register e.g., Down’s Syndrome. The NHS and Public Health England collect annual data for specific health and healthcare indicators from registers of all participating GP practices; similar data is also aggregated from a group of people without learning disabilities. Data is analysed at a national level and findings from comparative analysis are published in annual summary reports, which are also translated into easy to read formats.

## Origin / impetus for best practice
- Mencap advocated for the creation of a registry of people with learning disabilities ("Treat me Right!" report, 2004).¹
- The Independent Inquiry report (2008) revealed that people with learning disabilities experience higher levels of unmet need and receive less effective treatments than the general population.²

## Impact / results of implementing best practice
- Registers facilitate the identification of patients who are eligible for an annual learning disability health check and seasonal flu vaccination.
- New clinical codes associated to learning disabilities available after expert review.
- Projects derived from data collection e.g., national project to stop over medication (STOMP).

## Critical success factors for best practice
- Financial incentives for GPs who keep learning disability registers.
- Strong advocacy from the learning disability community.

## Impact statement
- Coding of clinical diagnoses should be standardized and consistent across datasets from practices.
- Coverage varies across the country and around 75% of people with learning disabilities remain invisible to data collection.³

## Sources
-¹ Mencap report 2004 Treat me right
-² Michael Report 2008
-³ Learning Disabilities Observatory 2016

## Further links & information
- NHS – Learning Disabilities and Autism
- Learning Disability Data
- NHS – Health and Care of People with Learning Disabilities, Experimental Statistics

## Involved actors
- Department of Health
- National Health Service (NHS) England
- Public Health England

## Lessons learned
- Coverage varies across the country and around 75% of people with learning disabilities remain invisible to data collection.
### Origin / impetus for best practice

- The concept of active rehabilitation for person with SCI/D stems from the idea that returning to society was a matter of self-determination of persons with SCI/D and can be achieved through sports and skills training.
- Despite existing guidelines on the healthcare for persons with SCI/D, no national programs for SCI care existed, especially long-term care and for community integration. FAR fills the gap between professional-run healthcare and life in the community.

### Impact / results of implementing best practice

- Improved motor function.
- Increased independence.
- Improved quality of life.
- Enhanced social integration and job opportunities with FAR.

### Critical success factors for best practice

- Having persons with SCI/D as the program facilitators, staff, and leaders of the organization.
- Collaborating with different sectors for programs, donations, etc.
- Strong connection with rehabilitation hospitals.

### Impact statement

- Persons with permanent SCI do not require continuous care for the rest of their lives, and do not have to be released from any responsibilities. They need skills which will allow them to regain their self-reliance, self-esteem, and a place in the society. This is where the Foundation for Active Rehabilitation steps in. It teaches people with spinal cord injury how to lead a normal life in a wheelchair, how to fulfill their dreams and achieve the goals they had before the accident.

### Involved actors

- Foundation for Active Rehabilitation (FAR)
- State Fund for the Rehabilitation of the Disabled
- Ministry of Family, Labour, and Social Policy

### Sources

- Tederko et al. 2017. People with SCI in Poland
- Kaminska-Gwozdz et al. 2018. Effect of FAR camps on the QoL of Individuals with SCI
- EU Resources on People with Disabilities

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**Autonomy and Awareness**

**Active Rehabilitation Services in Poland by and for people with disabilities**

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>National; Poland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Disability</td>
<td>Spinal cord injury/disorder (SCI/D), wheelchair users</td>
</tr>
</tbody>
</table>

**Involved actors**

- Foundation for Active Rehabilitation (FAR)
- State Fund for the Rehabilitation of the Disabled
- Ministry of Family, Labour, and Social Policy

**Best practice description**

FAR is an organization of persons with disabilities run and supported by persons with SCI/D that offers social and vocational activation programs to persons with SCI/D. FAR works with acute rehabilitation facilities to identify potential program participants and provides:

- Training camps where participants acquire practical daily skills (e.g. wheelchair training, activities of daily living, using transportation)
- Information about living with SCI/D
- Free wheelchair rental for the first year after hospital discharge
- Vocational skills training
- Vocational, social, and psychological counseling.

FAR also supports inclusive healthcare by training health professionals on disability issues related to SCI/D from the perspective of persons living with SCI/D and advocacy work. In addition to financing through the State Fund for the Rehabilitation of the Disabled (under the auspices of the Minister of Family, Labour and Social Policy), selected projects are financed by regional governments (e.g. Lodz), the European Union and the business community (e.g. Toyota).

**Further links & information**

- EU Resources on People with Disabilities
Autonomy and awareness
Peer educator training on sexual and reproductive health and rights of people with disabilities in Burundi

Geography and scale: Burundi; provinces of Mwaro, Muramvya and Gitega
Type of disability: All persons with disabilities with a focus on youth (10-24 years old)

Involved actors
- National Program for Reproductive Health, Ministry of Health of Burundi
- National Union of Burundi for people with disabilities (UPHB)
- Deutshe Gesellschaft für Internationale Zusammenarbeit (GIZ)
- Local health centres (14) and associations for people with disabilities
- Province and district health management teams
- Specialized educators for people with disabilities
- Youth with disabilities

Best practice description
Youth with disabilities were trained to become peer educators in sexual and reproductive health and rights (SRHR) of people with disabilities. The training was implemented in 2021 by UPHB in collaboration with GIZ. Peer educators then hold informative sessions for youth with disabilities in specialized centres and inclusive schools. SRHR are promoted among youth of different faiths and settings, depending on their specific needs and age groups. Key contents include SRHR, sexually transmitted diseases, contraception, body changes, physical, psychological and sexual violence, etc. Healthcare providers and other partners in the project area also participated in trainings about inclusive health for people with disabilities.

Origin / impetus for best practice
- In 2020, centres and associations for people with disabilities were identified in the provinces of Mwaro, Muramvya and Gitega to assess SRHR needs regarding health information and access to health services. This mapping and assessment was conducted by GIZ in collaboration with UPHB.
- People with disabilities in Burundi have poor access to SRHR education and are exposed to abuse. The specific needs of people with disabilities are not taken into account in health structures. There is a lack of health worker training on disability and SRHR, as well as a lack of adequate educational materials. In addition, health facilities have poor physical accessibility and health care providers tend to have discriminatory behaviour towards people with disabilities.

Impact / results of implementing best practice
- Improved knowledge of SRHR among youth.
- Training of 90 peer educators on SRHR.
- 52 information sessions on SRHR held by peer educators, reaching over 1500 youth with disabilities.
- Training of 43 healthcare workers and 2 partners on inclusive health for people with disabilities.

Impact statement
- A course on SRH was organised involving people with disabilities. Their participation is a first. Thanks to the training and contacts with the specialised structures, we are thinking of involving people with disabilities in our awareness-raising activities on SRH, Gaudence (caregiver, Fato).

Sources
- Training guide for providers in inclusive approaches, 2021, UPHB (Internal use)

Critical success factors for best practice
- Youth with disabilities as peer educators on SRHR.
- Topics covered and training methodology.
- Follow-up of peer educators after training and management of peer educators' turn-over.
- Collaboration with religious leaders, as they are the main support of organizations for people with disabilities.
- Funding from an international organization for SRHR and disability inclusion.

Lessons learned
- Collaboration with SRH stakeholder networks will help to reach people with disabilities in the community.
- Commitments made during training should be implemented and awareness-raising activities monitored.
- Future needs include provision of accessible equipment, refresher trainings, and experience sharing between stakeholders and other actors.

Date: Feb 2022
# 5 Autonomy and Awareness

## Autism and Mental Health Literacy Project (AM-HeLP) in Canada

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>Canada (but available online)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Disability</td>
<td>Autism Spectrum Disorder (ASD)</td>
</tr>
</tbody>
</table>

### Involved actors
- Centre for Addiction and Mental Health (CAMH)
- York University Developmental Disabilities and Mental Health Lab
- Autistic people and their families
- Spectrum Productions
- Public Health Agency of Canada

### Best practice description
The Mental Health Literacy Guide was developed to increase autistic adults’ awareness, knowledge, and acceptance of mental health. The guide has nine sections that focus on building awareness of mental health, particular mental health concerns and coping strategies for autistic people, and resources for support. The guide is targeted primarily at autistic adults and quotations throughout the document showcase the lived experiences of autistic adults to provide the most appropriate, relevant, and valid information. The guide follows two years of consultation with 29 autistic adults and family members of autistic adults from across Canada who spoke about their personal lived experiences. The advisers informed the structure, topics and content of the guide, including chapters on the definition of mental health, what it’s like to grow up autistic in Canada, strategies to maintain good mental health, appropriate identity-first language to use to talk about autism, signs of mental health problems and ways to promote well-being. The guide also includes information on the pandemic’s impact on autistic people and resources for families and others.

### Origin / impetus for best practice
- Lack of information about autistic people’s experience of mental health and mental health needs.
- No mental health literacy materials that talk about the intersection between well-being, mental health problems, and autism.
- Limited mental health resources that specifically incorporate autistic peoples perspectives.
- High rates of mental health or substance use disorders among autistic adults (~50%).
- Desire to create a more friendly, welcoming, and accepting environment of autistic mental health, as well as develop more autistic-informed mental health supports in Canada.

### Impact / results of implementing best practice
- A program evaluation is underway: researchers are interviewing autistic advisors to understand the experience of co-creating the guide and to develop lessons learned for the future.
- Involvement of autistic adults in designing and producing the guide’s content.
- Funding from government agencies for autistic mental health research.
- Plain-language summaries and accompanying videos/transcripts make it more accessible to all individuals.
- Specific sections focused on intersectionality.

### Impact statement
“One of the biggest myths we try to dispel in this guide is that autism is a mental health problem. Autism is not a mental health problem; it is a different way of being,” Dr. Jonathan Weiss, associate professor in the Faculty of Health and York Research Chair in Autism and Neurodevelopmental Disability Mental Health at York University and project lead on the guide (News@York).

### Critical success factors for best practice
- Importance of consulting and highlighting individuals with lived experience in guidelines.
- While action is important, individual awareness and autonomy can be critical to starting conversations on under-researched or underrepresented topics.

### Lessons learned
- Importance of consulting and highlighting individuals with lived experience in guidelines.
- While action is important, individual awareness and autonomy can be critical to starting conversations on under-researched or underrepresented topics.

### Sources

### Further links & information
The guide has been turned into an animated video series, which can be found on YouTube.
## Best practice description

The Accessible COVID-19 Vaccination program allows people with disabilities and those over 75 years of age to request free, accessible transportation to COVID-19 vaccination clinics. Individuals are eligible if they “are frail or have underlying conditions which make them at greater risk from COVID-19 and/or unable to safely access other modes of public transportation”. The program is available to residents of Toronto who meet the criteria and have an appointment at a city-run or health partner clinic. Community partners have been selected to ensure those who need to be vaccinated will be reached and Uber has donated $150,000 CAD of vouchers to community organizations. Metro and bus passes were also given to those who could take public transport but could not afford it.

## Origin / impetus for best practice

- Limited accessible transport options in Toronto city.
- Recognition that some individuals may not be comfortable using public transport because of their risk status, but need accessible and affordable transport to and from the vaccination centres.
- Input from people with disabilities on Toronto’s Accessibility Task Force on COVID-19 Vaccines and their desire to remove barriers to vaccination.

## Impact / results of implementing best practice

- Increased accessibility of vaccination.
- Reduced financial barriers to vaccination.

## Critical success factors for best practice

- Political will to remove barriers to vaccination.
- Involvement of community organizations.
- Strong disability involvement and dedicated accessibility task-force.
- Health equity considerations that included disability.

## Impact statement

“At the City of Toronto, we are committed to ensuring that every resident in every area of this city can easily access a COVID-19 vaccine when it’s their turn. To make this possible, we have adopted a Team Toronto approach that builds on partnerships and active collaborations and delivers on-the-ground support. The Vaccine Equity Transportation Plan is a great example of working together to help our community and remove barriers to accessing vaccines.” - Councillor Joe Cressy (Spadina-Fort York), Chair of the Toronto Board of Health

## Lessons learned

- Importance of disability representation on task forces and equitable, accessible approaches to COVID-19 response programs.
- Incorporating multiple accessible modalities of transport (i.e. public, private) and partnerships are key to reach individuals with disabilities.

## Sources

- Ontario Extending Free Rides to Vaccination Sites for People with Mobility Issues

## Further links & information

- Toronto’s Vaccine Equity Program
- Backgrounder on Toronto’s Accessibility Task Force on COVID-19 Vaccination
# Community Health Worker training to identify children with development disabilities

## Human Resources

### Geography and scale:
- Dehradun District, Uttarakhand, India

### Type of Disability
- Developmental Disabilities

### Involved actors
- Latika Roy Foundation
- Sight Savers
- Accredited Social Health Activists (ASHAs)

## Best practice description
Through a Sight Savers Innovation Grant, the Latika Roy Foundation trained Accredited Social Health Activist (ASHA) in four blocks of the Dehradun district (population: 754,753) on early intervention for children with developmental disabilities. As the Community Health Workers who visit homes for immunisation and maternal health programs. ASHAs also check on young infants. This program taught them to use the WHO tool to identify children with developmental disabilities or delays and refer them to the nearest early intervention centre. Over four months (February to May 2013), 18 ASHA facilitators were trained as master trainers by parents of children with developmental disabilities. From June onwards, these facilitators trained their own ASHA workers under supervision (320 total). Once these were completed by August 2013, follow up workshops were conducted on a monthly basis to understand current knowledge, application in the field and clarifications around understanding and implementation. Thereafter, each home visit would be accompanied by a short interview and assessment with the parents help to assess the development of infants and young children. Those who have been identified with potential delays are referred to the primary health center for further assessment and treatment.

## Origin / impetus for best practice
- Despite the high prevalence of disabilities, children were not being referred to early intervention services as much as they should and as early as they should.
- Limited access to community-based services in the rural, mountainous state of Uttarakhand, meant the best feasible option seemed to train the community health workers who visited homes in far and remote areas as part of their national program agenda.
- Families could not travel long distances for assessments and identification, limiting their ability to access local referrals for therapy for their children.
- Limited funding and acute scarcity of professionals to support children with disabilities.

## Impact / results of implementing best practice
- The program helped with identification of hundreds of children with developmental disabilities who received early intervention.
- Health care workers received new skills, which will also benefit the typical children in their caseloads. Beneficiaries included 560 children; 560 parents; 18 ASHA facilitators, and 320 ASHAs.

## Critical success factors for best practice
- Permission for training and implementation, as CHWs are over burdened with multiple government schemes.
- Salary for ASHA facilitators travel and time.
- Supervision and faith that tool would be implemented.
- Connecting with and motivating families to participate in an early childhood developmental evaluation.

## Impact statement
“Since the program commenced in January 2013, 133 children have been followed up. A total of 46 follow up programs have been conducted as of July 2013.” - Dr. Shubha Nagesh, Latika Roy Foundation

## Lessons learned
- Local level health workers can be trained effectively to identify children with disabilities and facilitate early intervention.
- Most interventions are simple for CHWs to learn, teach, and transfer to families of all literacy levels.
- Early intervention is critical, but sustained funding is necessary to ensure these programs continue.
- Additional knowledge helps parents and CHWs understand disability beyond observable features and improve evaluation of developmental milestones for all children.

## Sources

## Further links & information
German Disability-inclusive Nursing Practice Handbook

**Best practice description**
As part of the campaign of North Rhine-Westphalia (NRW) to implement the UNCRPD’s stipulations for equal access to healthcare for persons with disability (PwD), the “Competence Centres Self-determine Life (KSL)” in NRW developed a nursing practice handbook entitled “KSL-Concrete #4 Nursing Diversity” [KSL-Konkret #4 Vielfalt Pflegen]. This handbook was written to enhance nursing training with a compact reference guide on effective communication and interaction with PwD in routine practice, on recognizing the needs of PwD and acting accordingly. It aims to lend the nurse confidence in treating patients with disability by building skills and sensitizing the nurse to potential situations (case examples) in clinical routine. This is essential, since the nurse is often the first point of contact in the healthcare facilities and a person of trust. The KSL and their work are financed by the European Commission Social Fund and KSL Ministry of Employment, Health and Social Welfare.

**Origin/impetus for best practice**
To implement the idea that sustained improvement of life of PwD is a societal responsibility, NRW developed an action plan in 2012 “A society for all – NRW inclusive”. As part of this action plan, six competence centres (KSL) were created to ensure the self-determination of PwD and inclusive healthcare in NRW. These KSLs run diverse projects to meet these objectives, especially in the area of knowledge transfer and training. One of these projects was the development of this nursing practice handbook.

**Impact / results of implementing best practice**
The handbook has only been around since November 2020, but it will sensitize nurses and the public to inclusive health care issues.

**Impact statement**
"The knowledge acquired through this practical manual will give you confidence in communicating and in interacting with PwD. [By understanding what PwD need], you will save precious time and can focus on providing care. PwD will benefit, and so will you." - Claudia Middendorf, NRW parliamentarian responsible for PwD.

**Critical success factors for best practice**
- Government leadership.
- Training methodology.

**Lessons learned**
- Need to reinforce handbooks with training and other supports for people with disabilities.
- Essential to target nurses with training, given they are usually the first point of contact in care.

**Geography and scale:** Primarily the German state of North Rhine-Westphalia

**Type of Disability** All types

**Involved actors**
- Competence Centres Self-determine Life (KSL) [Kompetenzzentren Selbstbestimmt Leben]
- Ministry of Employment, Health and Social Welfare [Ministerium für Arbeit, Gesundheit und Soziales des Landes Nordrhein-Westfalen],
- Bochum Centre for Disability Studies (BODYS), Protestant University of Applied Sciences Rheinland-Westfalen-Lippe

**Sources**
KSL-Concrete #4 Nursing Diversity (German)
Eye care capacity building in low- and middle-income countries

**Human Resources**

**Origin/impetus for best practice**
Over 2 billion people in the world have lost all or some of their sight. At least 1 billion of them have a visual impairment that could have been prevented or treated. Loss of sight severely affects their participation in daily life, e.g. not being able to attend school or work.

**Best practice description**
To meet the aim of WHO’s and the International Agency for the Prevention of Blindness VISION 2020 global initiative to eliminate avoidable blindness, Light for the World with partners have offered cataract operations, distribute medication, train ophthalmologists, build and support hospitals, and provide mobile services that offer eye care in remote areas of low- and middle-income countries, especially in sub-Saharan Africa. Through this program, they set up several residency, optometry, ophthalmic technician, and eye care nursing programs to increase the number of eye-care workers domestically across sub-Saharan Africa. This has also created enough staff for mobile teams to support remote communities.

**Geography and scale:** Worldwide: focus on sub-Saharan Africa

**Involved actors:**
- Light for the World
- University Hospitals in Jimma and Gondar, Ethiopia
- Ministry of Health, Uganda
- Ministry of Foreign trade and Development Co-operation, Netherlands

**Type of Disability:** Visual impairment

**Impact / results of implementing best practice**
- 63 doctors are pursuing ophthalmology studies in African countries.
- Increase number of eye care staff through two residency programs at Univ. hospitals in Jimma and Gondar.
- 50 students were trained in clinical optometry, and nurses start with ophthalmology or further training.
- Eye clinic of Arba Minch has mobile teams that travel to remote areas.
- Burkina Faso established the country’s first national ophthalmology training program in the capital city.
- Mozambique supported the training of ophthalmic technicians and ophthalmologists.
- Partnership with the Ugandan Ministry of Health in the National Intervention on Uncorrected Refractive Errors project.

**Critical success factors for best practice**
- Successful coordination and engagement with multiple governments and stakeholders.
- Sustainable approach to providing services and increasing capacity.
- Mixed approaches (formal education, training, mobile teams) to have a large impact.

**Impact statement**
“We strive for effective solutions and high quality. We focus on sustainable and systematic changes, but at the same time also on direct impact and better living conditions for people with disabilities. Our first projects were focused on eye-care and inclusive education...Over the years, the breadth and diversity of the work have grown, and we direct more attention to the rights of persons with disabilities and the importance of inclusive societies.”

**Lessons learned**
- Importance of collaborative effort.
- Sustainable approach is necessary for long-term success.

**Sources**
- Light for the World

**Further links & information**
- Light for the World Annual Report
Starting in April 2021, the NHS has mandated that all health and social care staff participate in mandatory training programs to meet the needs of people with learning disabilities and autism. The program is based on the 2019 Capabilities Frameworks that provide guidance for supporting people with learning disabilities and autism. As part of a pre-service training and professional development program, health and social care workers will be exposed to a curriculum that looks at:

i) Understanding learning disabilities and autism
ii) Personalized support
iii) Physical and mental health
iv) Risk, legislation, and safeguarding
v) Leadership and management, education and research.

The program was designed in collaboration with people with disabilities and will be delivered by individuals with lived experience through face-to-face delivery and blended learning approaches. The program is administered to different tiers of health workers in either two half-day sessions or two full-day sessions (or both).

LeDeR mortality review and Mencap reports demonstrated the need for better training to improve knowledge, skills and awareness of learning disabilities and autism among health and care professionals.
The UK Government decided to consult people with learning disabilities and autism to implement a mandatory training for health workers.

Over 5,000 people participated in the consultation process to develop the training.
1.2 million NHS staff and 1.5 million adult social care staff in England are expected to take part in the training, when it is fully implemented.
### Best practice description

In 2017, a handbook on sexual and reproductive health services for people with disabilities was developed and distributed to health care professionals in Ecuador’s national health system. With a special focus in primary care, it aims to ensure there are quality services that respond to the particular needs of people with disabilities. Based in a human-rights framework, it also aims to strengthen sexual and reproductive health information and counselling for people with disabilities, as well as the exercise of their rights. The handbook provides technical guidance, general recommendations and specific advice by type of disability on: attitudinal, communicational and physical accommodations; autonomy, independence and informed consent; use of contraceptives; pregnancy, childbirth, postpartum and new-born care; and prevention of sexual violence.

### Origin / impetus for best practice

- Ecuador subscribes to a human rights framework to address disability and acknowledges at the constitutional level that persons with disabilities are a priority group with recognized rights of access to specialized health care, free medications, comprehensive rehabilitation, and assistive technology.
- The Ministry of Health’s National Plan for Sexual and Reproductive Health 2017–2021 promotes inclusion, equality and respect for human rights within the framework of sexual and reproductive health.
- Ecuador was involved in the “We Decide” programme led by the United Nations Population Fund that promotes the human rights and social inclusion of women and young persons with disabilities.
- Gender-based and sexual violence was found to be higher among women with disabilities than those without in Ecuador.

### Impact / results of implementing best practice

- First national workshop of 2019 strengthened inter-sectoral coordination and plans further implementation of the handbook, including the correct use of the contraceptive methods booklet in Braille language.

### Critical success factors for best practice

- Technical support of international organizations.
- Participation of a broad range of stakeholders, including people with disabilities.
- Disability-inclusion in the country’s political agenda.

### Impact statement

- ...
- ...
- ...

### Lessons learned

- ...
- ...
- ...

### Sources

- State party report 2018 UNCRPD

### Further links & information

- Young persons with disabilities: Global study on ending gender-based violence, and realising sexual and reproductive health and rights, 2018, UNFPA
Geography and scale: Dar es Salaam, Tanzania

Type of disability: All types

Involves actors
- Comprehensive Community Based Rehabilitation in Tanzania (CCBRT)
- Ministry of Health, Community development, Gender, Elderly and Children, Tanzania
- Tanzanian Nursing and Midwifery Council
- Kupona Foundation

Best practice description
CCBRT is the largest provider of disability and rehabilitation services in Tanzania. Through its academy, it offers specialist training for health care professionals on disability inclusion in health care services. A two-day training course aims to provide trainees with an understanding of the concept of disability-inclusive health services and the barriers and benefits of such services for people with disabilities. It is directed at CCBRT staff and representatives of development organizations. The course is based on a human-rights framework and it is delivered through lessons and workshops. After completion, participants receive certificates of attendance and six CCBRT credits.

Origin / impetus for best practice
- The CCBRT Academy started offering external trainings in 2018 in a response to the shortages in human resources for health and limited access to continuing professional training, as well as a sustainability strategy for the organisation.
- The disability inclusion in health care services training is part of a disability and inclusion program that offers courses on the general concept of disability, advocacy, Kiswahili sign language, accessibility, and disability inclusion in the workplace and schools.

Impact / results of implementing best practice
- In 2019, 1,044 people were trained through the academy.
- Increasing number of persons with disabilities who are coming to health facilities to access health care services.
- Improved access of physical infrastructure of the newly constructed health facilities (ramps, toilets, elevators, etc.).
- There has been some initiatives by the Ministry of Health and some partners to produce information on health in accessible formats (Braille and sign language).

Critical success factors for best practice
- Long-standing experience in capacity building and education.
- Sustainable approach.
- Strategic partnerships with academic institutions, philanthropists, sponsors and health care providers.

Impact statement
- Continuous learning of healthcare providers on disability inclusive approaches is crucial to ensure sustainability.
- Capacity building to health care providers has to go hand in hand with development and dissemination of National Guidelines on Disability Inclusive Health Care Services.
- People with disabilities need to be empowered on their rights to healthcare services and be informed on availability of those services in their localities.

Sources
- CCBRT official webpage
- CCBRT Academy

Further links & information
- CCBRT Academy Training Catalog 2019-2020
### Human Resources

#### Future Learn: Improving Health Assessments for People with Intellectual Disabilities

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>Internationally accessible, online</th>
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</thead>
<tbody>
<tr>
<td>Type of disability:</td>
<td>Intellectual Disabilities</td>
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</table>

**Involved actors**
- Future Learn
- Trinity College Dublin (TCD)
- EIT Health

**Best practice description**

The FutureLearn platform provides free and open online courses, including “Improving Health Assessments for People with Intellectual Disability”. The aim is to provide healthcare practitioners the knowledge to improve practice and include reasonable adjustment when engaging individuals with intellectual disability in health assessments. The course is taught through a partnership between Trinity College Dublin and EIT Health and was co-developed by people with intellectual disabilities to train health workers on improving care. The content focuses on health inequity, the healthcare landscape for people with intellectual disabilities, communication skills, reasonable adjustments, and best practices for assessing patients with intellectual disabilities. The course is accredited by the Nursing and Midwifery Board of Ireland and can be used as continuing professional development, in some jurisdictions. It provides two hours of content per week over three weeks.

**Origin / impetus for best practice**

- A previously developed comprehensive health assessment demonstrated the need for more implementation support and health worker training.
- Deinstitutionalization resulted in increased involvement of primary care doctors in health care for people with intellectual disabilities
- Higher prevalence of health conditions, health inequity, and lack of reasonable adjustments to ensure they actually are invited to health assessments, which contributed to high rates of undiagnosed or untreated health conditions among people with intellectual disabilities

**Impact / results of implementing best practice**

- Over 7,000 healthcare professionals have enrolled in the course in over 100 countries.
- The MOOC is now integrated as part of a module on the intellectual disability nursing programme of TCD Dublin.
- Expansion to post graduate programming in intellectual disability for healthcare professionals at TCD Dublin.
- 87.5% of participants noted a change in perspective about assessing people with ID, 83% noted a change in their approach to communication and 79.1% noted it contributed to their day to day work to make health assessment possible.

**Origin / impetus for best practice**

- Over 7,000 healthcare professionals have enrolled in the course in over 100 countries.
- The MOOC is now integrated as part of a module on the intellectual disability nursing programme of TCD Dublin.
- Expansion to post graduate programming in intellectual disability for healthcare professionals at TCD Dublin.
- 87.5% of participants noted a change in perspective about assessing people with ID, 83% noted a change in their approach to communication and 79.1% noted it contributed to their day to day work to make health assessment possible.

**Critical success factors for best practice**

- Online, flexible, and free materials continuously available
- Course was co-designed with people with intellectual disabilities
- Ability to use the course hours for Continuing Professional Development and courses’ accreditation
- Course provides practical techniques for adapting clinical practice
- Integrated into the undergraduate nursing curriculum at TCD Dublin

**Impact statement**

"The program has been absolutely fabulous, it is so needed and a great boost to everyone, promoting better practice when dealing with people with ID".

Dr Eilish Burke, Ussher Assistant Professor at TCD Dublin.

The creator also noted that this course provides targeted education in a convenient way for the learner promoting education and improvement to healthcare delivery for people with intellectual disability.

**Lessons learned**

- Wide reach and impact of a short course that is widely available.
- Importance of providing practical technique alongside clinical background.
- Need for robust research to inform evidenced based practice.

**Sources & Useful Links**

- Future Learn Website
- Making Reasonable Adjustments to Support People with Intellectual Disabilities in Health Assessments
- Health Assessment Impact Video

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Date: April 2021
Disability Training for Community Health Assistants in Zambia

**Involving actors**
- Ministry of Health (MoH)
- Zambia Institute for Special Education
- Clinton Health Access Initiative (CHAI)
- United States Agency for International Development (USAID)

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<thead>
<tr>
<th>Geography and scale:</th>
<th>Zambia, National</th>
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<tr>
<td>Type of Disability</td>
<td>All types</td>
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**Best practice description**
In 2019, the Clinton Health Access Initiative (CHAI) worked with the Government of Zambia in facilitating a 5-day training aimed at improving Community Health Assistants’ (CHAs) skills and capabilities for inclusive patient-focused healthcare to persons with disabilities. The program trained Ministry of Health (MoH) staff, and tutors and clinical instructors at the two main CHA training schools. By focusing on the teachers and liaisons who work daily with CHAs, the objective was to determine together ways to incorporate greater understanding of the health needs of people with disabilities, and the barriers they face when seeking healthcare, into the education and assessment of CHAs going forward. The training focused on:
1) The unique health system experience of people with disabilities
2) Communication skills (e.g., engagement and communication with children with autism), and introductory sign language
3) Teaching skills in orientation and mobility content to students with visual impairment
4) Use of assistive devices, and other neurological disorders

**Origin / impetus for best practice**
- In Zambia, CHAs play an important role by filling the gap and increasing access to basic health services for rural communities.
- In 2016, the Zambian MoH conducted a curriculum review of the CHA training program and found that CHAs were not being trained on disability inclusiveness. Questions arose as to whether tutors had the required skills and knowledge to teach students disability inclusiveness.
- CHAI, in partnership with the MoH, and USAID under the Community Health Assistants Support Activity, developed this pilot initiative to improve tutors’ understanding and comfort around teaching disability inclusiveness.

**Impact / results of implementing best practice**
- Training of 19 tutors (most were nurses and others were environmental health technologists).
- Trainees acquired skills in Zambian sign language and other modes of communication.
- Disability modules will be developed and included in all CHA training schools.

**Impact statement**
“[I see a great improvement in health services, as most clinics and hospitals have trained health workers in sign language. More awareness and training in disability is needed so that in the next three years disabled people in Zambia are assured of better health”](Image 533x882 to 763x1050)

Mukuma Chiwata, deaf lecturer at the Zambia Institute of Special Education.

**Critical success factors for best practice**
- Curriculum review of the CHA training program.
- Early involvement and commitment of the MoH.
- Training conducted by a disability specialist hired by the MoH.
- Sufficient time provided for each trainee to familiarize themselves with the training materials and the inclusion of practical sessions.

**Impact / results of implementing best practice**
- Training of 19 tutors (most were nurses and others were environmental health technologists).
- Trainees acquired skills in Zambian sign language and other modes of communication.
- Disability modules will be developed and included in all CHA training schools.

**Lessons learned**
- Trainees were more receptive to content on sign language and neurological disorders than deafness or blindness. Therefore, more practical sessions and videos about this topic would be ideal.
- Advanced medical terms in sign language should be taught.
- Certified health training schools need a comprehensive disability inclusion curriculum and the MoH should extend disability training to frontline staff.

**Sources**

**Further links & information**

USAID/Zambia Health - Community Health Assistants Support Activity

About: The Community Health Assistants Support Activity ran from March 2019 to June 2021. The overall purpose of the activity was to improve access to cost-effective, quality basic health and nutrition services at community level and in health posts across eight provinces (Central, Copperbelt, Eastern, Luapula, Muchinga, Northern, North-Western, and Western).

Date: March 2022
# Home Testing for COVID-19 in the United Arab Emirates

## Best practice description
To ensure universal access to COVID-19 testing, the United Arab Emirates launched home testing for residents with disabilities who may otherwise not be able to access a COVID-19 testing facility. In particular, the program targets individuals with mobility and communication disabilities for whom travelling to a testing centre or communicating with health workers is challenging. Individuals or their families can call a number to book an appointment when a specialized team will come by the home to do the test. The program also expands drive-through testing facilities, which has also increased access for some people with disabilities.

## Origin / impetus for best practice
- Desire to ensure all citizens and residents had access to preventative and diagnostic measures, such as testing
- Government’s priority to include people with disabilities in mainstream programs, as well as targeted programs to ensure health and safety

## Impact / results of implementing best practice
- Reduced barriers to getting tested for COVID-19
- Enhanced accessibility for people with disabilities

## Critical success factors for best practice
- Government effort to identify barriers and address them through targeted programs
- Sufficient resources (Human resources for health, personal protective equipment, tests, etc.) to provide at-home testing

## Lessons learned
- Two-tracked approaches (universal access and targeted programs) are critical to meeting the health needs of people with disabilities
- Governments need to identify and find innovative ways to address gaps in services for people with disabilities, such as home-based services where feasible

## Sources
- United Arab Emirates National Home Testing Program for People of Determination

## Further links & information
- Mohamed bin Zayed launches ‘National Home Testing Programme for People of Determination’
- Coronavirus: UAE launches home testing option for ‘people of determination’

*People with disabilities are referred to as ‘people with determination’ in the UAE*
### Annual Health Checks for people with learning disabilities in the UK

#### Best practice description
People with learning disabilities 14 and over who are registered with a general practitioner (GP) are entitled to a free annual health check. Established in 2008, this programme aims to prevent, detect and treat new and unmet health needs in a timely fashion. Health checks include:

- Physical examinations the patient consents to (e.g., weight, blood pressure, blood samples, etc.)
- Chronic diseases and mental health exam, emphasizing commonly associated conditions (e.g., epilepsy, constipation, dysphagia, etc.)
- Health promotion and review of immunizations and medications.

Accommodations are made whenever necessary, such as additional time, easy to read information, suitable appointment time and support from companions or carers. All of this information is registered in each patient’s profile. The GP should help develop a health action plan after the health check and facilitate referrals to any secondary care.  

**Sources:**
- Learning and Autism – Annual Health checks – NHS
- Annual Health Checks NHS
- Guidance Annual health checks and people with learning disabilities
- Confidential Inquiry, 2013

#### Origin / impetus for best practice
- People with learning disabilities face health inequalities; they often have poorer physical and mental health than the general population.
- People with learning disabilities may be unaware of the medical implications of symptoms they experience, have difficulty communicating their symptoms or may be less likely to report them to medical staff.
- The Confidence Inquiry (2013) into the deaths of people with learning disabilities recommended the standardisation of Annual Health Checks and a clear pathway between the Annual Health checks and Health Action Plans.

**Critical success factors for best practice**
- GPs receive financial incentives for completing annual health checks.
- Existence of a National Electronic Health Check clinical template
- Existence of a National Health Check toolkit for general practitioners.

#### Impact / results of implementing best practice
- From 2019 to 2020, about 58% of people with a learning disability, who are on their GP’s learning disability register, had a health check.

**Impact statement**

**Lessons learned**
- Not all GPs do health checks but the number is increasing.
- Not all GPs report giving health action plans.
- Coverage of annual health checks varies considerably across the country.

**Sources**
- Annual Health Check film by NHS
- Mencap’s Don’t Miss Out! video campaign and stories
- Mencap Don’t Miss Out! website

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[Image: Click on the image to view larger version.]

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**Geography and scale:** England; national.

**Type of disability and age group:** People with learning disabilities aged 14 and over.

**Involved actors**
- National Health Service (NHS) England
- Public Health England
- Mencap

**Don’t Miss Out - Annual Health Checks**
If you have joined the learning disability register, you might be able to have a free Annual Health Check.

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**Date:** March 2021
**Wheelchair user training in El Salvador, India, Kenya, Nicaragua, and Romania**

<table>
<thead>
<tr>
<th>Geography and scale:</th>
<th>El Salvador, India, Kenya, Nicaragua, and Romania</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Disability</td>
<td>Wheelchair users</td>
</tr>
</tbody>
</table>

**Involved actors**
- World Vision
- Citizen and Voice Action (CVA)
- Motivation UK
- Motivation Romania
- UCP – Wheels for Humanity

**Best practice description**
With the goal of strengthening the wheelchair service sector through enhanced service capacity, provision of diverse range of wheelchairs, engagement with national and local governments and increased participation of wheelchair users, World Vision implemented the USAID funded ACCESS project in five countries (El Salvador, India, Kenya, Nicaragua, and Romania) from 2014 to 2017 following WHO’s 8+ model. The programme helped provide wheelchairs and train users and technicians to increase wheelchair user’s independence, knowledge about disability rights, and engagement with other people with disabilities. The program partnered with local organizations of persons with disabilities to ensure the sustainability of the programme at service centres for assistive devices.

**Origin / impetus for best practice**

> WHO estimates that only 5-15% of the 70 million people relying on wheelchairs for basic mobility have access to appropriate devices. In the absence of appropriate devices, a person with disability cannot be expected to participate in society fully and effectively, and would be excluded from many of the rights granted by national laws and the UN CRPD.”

**Impact / results of implementing best practice**
- 8,019 needs assessments and 7,319 wheelchairs, tricycles, or wheelchair improvements were distributed.
- 911 service providers were trained with wheelchair service skills at 43 service centers.
- 92% of users reported increased accessibility, inclusion, mobility, function, and participation.

**Critical success factors for best practice**
- Uptake of service provisions and effective capacity building using the Service Assessment Monitoring and Evaluation Tool.
- Qualitative data to assess community participation of wheelchair users.
- Qualitative data on enabling and impeding factors in social participation.

**Impact statement**
Wheelchair service goes beyond providing the service itself, it extends to “educating communities on appropriate wheelchair service and disability inclusion, facilitating inclusive communities, collaborating with a range of partners, and advocating not only for appropriate service to be mandated in laws and policies but also for disability inclusion at large.” [*ACCESS project document*]

**Lessons learned**
- Engagement with local/national governments important to address infrastructure accessibility issues.
- Need to strengthen, coordinate, and provide resources for community-based referral network.
- Important to have adequate wheelchair supply, transformation to digitalized databases and combat self-exclusion due to internalized stigma.

**Sources**

1. *Accelerating Core Competencies for Effective Wheelchair Service and Support (ACCESS) Project*

**Further links & information**

Wavinya’s Wheelchair helps fuel her dream of the skies
Comprehensive community based rehabilitation in Tanzania

**Best practice description**

CCBRT is the largest health care provider of disability and rehabilitation services in Tanzania. It aims to empower people with disabilities, improve their quality of life and ensure affordable and high quality access to specialized health care. Through an income adjusted fee scheme, services are provided through their four main health facilities: a disability hospital, two private clinics, and one rural rehabilitation centre. Some core services include ophthalmology, physical rehabilitation, orthotics and prosthetics, plastics and reconstruction. In addition, the organization has a Disability Advocacy Unit, an academy, a dedicated Maternal Newborn Wing with an associated capacity building program, and a disability inclusive sexual and reproductive health centre that encourages early diagnostics of birth defects. CCBRT is also the largest provider of fistula surgical care in Tanzania, and a FIGO accredited training site, with over 600 surgeries a year on average. All clinical areas provide specialized surgery and paediatric care, as well as clinical and social support for persons with disabilities and their families/caregivers.

**Origin / impetus for best practice**

- According to the World Health Organization, there are 10 million people in Tanzania experiencing conditions that could benefit from rehabilitation.
- The country has a shortage of skilled health workers, with only 7 health professionals per 10,000 inhabitants and a third of health facilities are resourced to perform basic service provision.
- CCBRT started providing community based rehabilitation services for children and adults with blindness in 1994 and quickly realized the extended need for comprehensive disability care.
- In addition, CCBRT aims to fill gaps in Dar es Salaam’s health system, which was built for a capacity of 750,000 patients, and in the context of a rapidly growing population of 6 million and an estimated disability prevalence of 9%.

**Impact / results of implementing best practice**

- In 2019, the Orthopaedics and Physical Rehabilitation department of the disability hospital conducted 28,855 consultations (assistive devices, prostheses, orthotics, physical and/or occupational therapy). The rural rehabilitation centre assisted 4,022 patients and provided 580 wheelchairs and assistive devices.

**Critical success factors for best practice**

- Long-standing experience in specialized care.
- Sustainable approach; the organization is transitioning towards a financially sustainable social enterprise.
- Strategic partnerships with academic institutions, philanthropists, sponsors and health care providers for financial and technical support.

**Impact statement**

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**Lessons learned**

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**Sources**

- CCBRT official webpage
- 2018-2022 CCBRT Strategy
- CCBRT Annual Report 2019

**Further links & information**

- World Health Organization Rehabilitation Need Estimator - Tanzania
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Date: July 2021
# National Rehabilitation Plan in Ukraine

## Best practice description

In 2015, Ukraine developed a National Disability, Health and Rehabilitation plan to improve rehabilitation services within the health care system, based in a technical consultation process conducted by a rehabilitation advisory team. Main actions and implementation projects included:

1. Establishment of a new rehabilitation department within the Ministry of Health and an inter-ministerial committee.
2. Translation and local adaption of rehabilitation terminology of the International Classification of Functioning, Disability and Health (ICF) into Ukrainian.
3. Establishment of procedures to conduct a population-based disability survey using internationally recognized methods.
4. Establishment of new curricula and rehabilitation professionals (physical and rehabilitation medicine (PRM) physicians, prosthetist-orthotists, speech and language therapists, physical and occupational therapists).
5. Implementation of model rehabilitation services for acute, post-acute and long-term phases.

## Origin / impetus for best practice

- Since 2014 the armed conflict in Eastern Ukraine has resulted in an increased demand for rehabilitation services.
- Ukraine had a rehabilitation system predominantly based on a biomedical model of disability and therapy focused on compensation of functional deficits and different kinds of social support.
- Essential rehabilitation professionals were absent and there was a lack of intersectoral coordination between governing bodies providing rehabilitation services.

## Impact / results of implementing best practice

- PRM physicians of the European Society conducted 26 courses (160 hours) to train 26 regular trainers from Ukrainian Medical Universities; in 2020, Ukraine had 283 local PRM physicians.
- The first class of Occupational Therapy Master students enrolled in September 2019.
- Since 2020, three packages of rehabilitation services are included in the national Programs of Medical Guarantees.

## Critical success factors for best practice

- Ongoing health care reform of secondary and tertiary levels of care.
- High level of political will and commitment of experts.
- Participation of people with disabilities in the technical consultation process.
- Collaboration with European and internationals partners.
- Raising awareness and information campaigns about the importance of rehabilitation services.

## Lessons learned

- Appropriate health care legislation is required for developing modern rehabilitation services.
- Continuing education for rehabilitation professionals is needed.
- ICF and its biopsychosocial approach should be implemented at a higher pace and at all stages of the rehabilitation process.

## Sources


## Date

May 2021