

National disability data streamlining and registry

<u>Organisation(s):</u>	Agenzija Support With: Ministry for Inclusion; National Statistics Office; Commission for the Rights of Persons with Disabilities	
<u>Country:</u>	Malta	
<u>Contact:</u>	policy@esn-eu.org	
<u>Theme:</u> Choose at least one option	<input type="checkbox"/> Ageing & Care <input type="checkbox"/> Asylum & Migration <input type="checkbox"/> Young People <input type="checkbox"/> Support for Children & Families <input type="checkbox"/> Community Care <input type="checkbox"/> Integrated Care & Support <input type="checkbox"/> Co-Production <input checked="" type="checkbox"/> Disability <input type="checkbox"/> Housing & Homelessness <input type="checkbox"/> Artificial Intelligence <input checked="" type="checkbox"/> Digitalisation <input checked="" type="checkbox"/> Quality Care	<input type="checkbox"/> Labour Market Inclusion <input checked="" type="checkbox"/> Social Inclusion <input type="checkbox"/> Technology <input type="checkbox"/> Workforce and Leadership <input checked="" type="checkbox"/> Social Benefits <input type="checkbox"/> EU Funding <input type="checkbox"/> Social Service's Resilience <input type="checkbox"/> Mental Health <input checked="" type="checkbox"/> Person-Centred Care <input checked="" type="checkbox"/> Research & Use of Evidence <input type="checkbox"/> Other, please specify:
<u>Principles of the European Pillar of Social Rights:</u> Check the 20 principles here .	<input type="checkbox"/> 1. Education, training, life-long learning <input type="checkbox"/> 2. Gender equality <input type="checkbox"/> 3. Equal opportunities <input type="checkbox"/> 4. Active support to employment <input type="checkbox"/> 5. Secure and adaptable employment <input type="checkbox"/> 6. Fair Wages <input type="checkbox"/> 7. Transparent employment conditions <input type="checkbox"/> 8. Social Dialogue <input type="checkbox"/> 9. Work-life balance <input type="checkbox"/> 10. Healthy, safe work environment	<input type="checkbox"/> 11. Childcare and child support <input checked="" type="checkbox"/> 12. Social protection <input type="checkbox"/> 13. Unemployment benefits <input type="checkbox"/> 14. Minimum income <input type="checkbox"/> 15. Old age income and pensions <input type="checkbox"/> 16. Health care <input checked="" type="checkbox"/> 17. Inclusion of people with disabilities <input type="checkbox"/> 18. Long-term care <input type="checkbox"/> 19. Housing and assistance to the homeless <input checked="" type="checkbox"/> 20. Access to essential services
<u>Current status of the practice:</u>	<input checked="" type="checkbox"/> Concept and Design Phase <input type="checkbox"/> Execution & Monitoring Phase <input type="checkbox"/> Consolidation Phase <input type="checkbox"/> Scaling Up and Transformation Phase <input type="checkbox"/> Other (please specify)	
<u>Context/ Social issues addressed</u>	The initiative began following the launch of Malta's National Strategy on the rights of disabled persons, called "Freedom to Live." The Ministry of Inclusion's Directorate for	

<p><i>Please explain the problem you attempt to solve.</i></p>	<p>Disability Issues facilitated a working group from 2024 to address the strategy's objectives. This initiative aligns with UNCRPD Article 31 and SDG Target 17.18.</p> <p>It addresses the problem of inaccurate disability-related statistics in Malta, which stems from underreporting or misreporting disabilities. Integrating various data sources and improving data collection processes aims to obtain more accurate, standardised, and comprehensive information to better understand the needs of persons with disabilities, allocate resources, and advise policymakers more effectively.</p>
<p>Objectives: <i>Please provide a maximum of three objectives in bullet points.</i></p>	<ol style="list-style-type: none"> 1. To develop a 'National Disability Data Register' by integrating disparate data sources and collaborating with various stakeholders, including the Ministry for Inclusion, Voluntary Organisations and Consumer Rights, Aġenzija Sapport, the Commission for the Rights of Persons with Disability (CRPD), and the National Statistics Office (NSO). 2. To centralise the services, improve data collection processes, and implement a cross-sector Case Management System integrated with the National Registry. 3. To gain a holistic view of disability-related statistics in Malta, address inaccuracies in reporting on national and international levels, and provide crucial data for future planning and policymaking.
<p>Activities: <i>Please summarise the activities put in place to achieve the objectives (maximum 300 words).</i></p>	<p>Aġenzija Sapport's role in this practice involves implementing and centralising its own services and Case Management System with national databases for Blue Parking Badges and EU Disability Cards for Maltese persons with disabilities. Further collaboration with the Ministry of Health is required to enhance data collection at the diagnosis level.</p> <p>The Agency's Quality Audit, Research, and Innovation (QARI) Department analyses statistics and stakeholder feedback to propose improvements and ensure operational quality. This aligns with ISO standards and the Agency's strategic objectives, which are aligned with the UNCRPD, including its definition of disability. The Department identifies inaccuracies and risks, including having separate registries from the National Identity system.</p> <p>The QARI Department is directly involved in the working group coordinated by the Directorate for Disability Issues (DDI) within the Ministry for Inclusion. It provides input on the type and method of data collection pertinent to the agency's services and schemes and the most frequently received requests from national and international bodies. The current national Census questionnaire is under review, and consultation with the UK's Office for National Statistics is planned to improve how information about disability is collected, analysed and reported in Malta. Outcomes from this consultation process are expected to provide structured guidelines on collecting and recording data by Aġenzija Sapport.</p>
<p>Outcomes: <i>Please explain what the results were/are so far and how you evaluated this.</i></p>	<p>As an ongoing practice:</p> <ul style="list-style-type: none"> - Aġenzija Sapport continues to consolidate the data and information collected internally, reducing duplication of work and reducing bureaucratic processes. This practice, which undergoes regular review and monitoring, offers insight into the challenges and risks on a smaller scale, providing valuable information to advise the development of the national registry on a larger scale. - The working group coordinated by MIV's DDI continues to review the data currently collected by stakeholders within the disability sector and determines its relevance and value for the exercise. - The working group requested other national stakeholders to inform if any disability-related data is collected and how this is done in other sectors. - The working group continues to assess the impact of implementing such a registry on service and legal restructuring, resource allocation, and strategic objectives by scrutinising budget allocations, service waiting lists, and disability-aggregated data

	<p>collected from various sources. This also includes risk and compliance assessments.</p> <ul style="list-style-type: none"> - Other outcomes include identifying the need for additional professionals to develop and integrate the required systems for data consolidation between state entities. - It has been determined by the working group that the Health Ministry is essential in bridging the gaps between disability diagnosis, support, services, and planning. Thus, further meetings with this ministry are planned to determine how such data can be integrated.
<p><u>Links to supporting documents:</u> e.g. website or report of the practice</p>	<ul style="list-style-type: none"> • Freedom to Live Document: https://inclusion.gov.mt/wp-content/uploads/2023/04/Disability-Doc-ENG-SEP-21.pdf • Aġenzija Sapport website: https://sapport.gov.mt/ • Ministry for Inclusion website: https://inclusion.gov.mt/ • CRPD website: https://www.crp.org.mt/ • NSO Malta website: https://nso.gov.mt/
<p><u>Comments and tips i.e. for people willing to use your Practice</u></p>	<ul style="list-style-type: none"> • Emphasise the importance of collaborating with various stakeholders, including government ministries, statistical offices, and disability rights organisations. This multi-faceted approach is crucial for creating a comprehensive and accurate data registry. • Prioritise the development of integrated Case Management Systems that can connect with national databases and identity registers. This integration is key to streamlining data collection and improving accuracy. • Ensure that all data collection and management processes comply with relevant data protection regulations (i.e., GDPR in the EU) to protect the privacy of persons with disabilities. • Consider all aspects of disability, including physical, mental, and hidden disabilities, to create a truly comprehensive registry. • Implement a robust evaluation process to assess the initiative's impact on service restructuring, resource allocation, and reporting accuracy. • Develop strategies to address underreporting and stigma associated with disability, which may affect data accuracy. • Ensure that the data collection and categorisation methods align with international standards such as the UNCRPD to facilitate comparability and reporting. • Provide thorough staff training on data collection and management to ensure consistency and accuracy. Depending on the context of the stakeholders involved, this training may extend to sessions on disability, diversity, and inclusion. • Involve persons with disabilities in the design and implementation process to ensure the system meets their needs and respects their rights. • Involve various experts from different sectors to identify key variables and share experiences when dealing with information requests or data requirements. • Design the system with scalability in mind, allowing for future expansion and integration with other relevant databases or systems.