Founding process of a registry of people with disabilities – methodological challenges and overcoming strategies[*]

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The benefits of having a database or registry of people with disabilities, met-hodological obstacles and their overcoming strategies are identified in this current topic. Benefits include a summarization of the clinical and demo-graphic profile of disabilities at a particular geographic region, providing support for overcoming systemic barriers, improvement of health policy, spe-cial services recognition and rendering, customized programs and regulated management of available resources. Methodological barriers refer to the lack of standardization in case-by-case assessments and the consequently que-stionable accuracy of diagnostic and anamnestic data. Attention should be paid to the use of various definitions, classifications and coding algorithms. The quality of data obtained from systems that were primarily founded for administrative and financial purposes may differ significantly from the data collected by analysing internal databases of health and educational or social welfare institutions. As a conclusion, important steps for the initiation pro-cess of founding a national or regional database or registry of people with

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disabilities are introduced and listed. They should incorporate an analysis of the implementation of various founding models, appropriate strategies selection, an examination of available data sources and information systems, verification of data standards, and methodology of collecting data, including an electronic exchange of health-related data.

Key words: *database, population-based study, disability, research, Serbia*

Introduction

Considering the position of the population of people with disabilities, there is an undeniable responsibility to systematically and continuously address emerging problems and different challenges in their everyday life situations. As known, life-long disorders can cause a heterogeneous and wide spectrum of impairments, numerous functional limitations, difficulties, complications and comorbidities. Nonetheless, such a status requires both continuous and comprehensive medical and rehabilitation services. Also, some environmental factors represent barriers to a person's functioning and have to be removed or modified, whereas those factors that facilitate or improve a person's performance should be recognized and reinforced.

Nowadays, disability studies are conducted at the population level, whether national, international or both. These studies are based on empirical data gathered through national or international registers. Registers are primarily created and used for the prospective longitudinal collection of data on aetiology, demographics and functioning. This cooperative inter-institutional connecting at the level of health, education and social welfare systems generally improve the quality of data, upgrade their collection methods and promotes knowledge dissemination (Hurley et al., 2015). In return, population-based research encourages connecting of the existing resources, support overcoming systemic barriers, thus resulting in sustainable and appropriate screening programs and improved detection of developmental disorders at an early age and their follow-up.

However, at our national level, this type of research is not sufficient. As a consequence, it is difficult to identify the characteristics and risk factors for different forms of disabilities and to propose and implement appropriate prevention measures. This contemporary and unresolved issue has both theoretical and practical relevance. Therefore, this paper aims

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to acknowledge the importance of a national and/or regional database or registry of people with disabilities and some of the benefits of their founding, as well as to examine the initial steps of founding process. Additionally, the relevant methodological obstacles are analysed, followed by the discussion of the appropriate overcoming strategies.

Importance and advantage of establishing a registry of people with disabilities

Families are increasingly encouraged to take an active role in health care, rehabilitation and education of their child with disabilities (Milićević & Klić, 2014). On the other hand, taking care of a child with disabilities is often a source of stress and burden on parents and requires continuous and comprehensive support (Bulić et al., 2012). Overall health policy improvement should include both development and implementation of adequate services and flexible programs and controlled redirection of available resources (Institute of Medicine, 2012). Still, in order to respond to the needs of people in this population, the first step is to better understand their health status and the factors that affect their functioning, activities of daily living, social inclusion and quality of life. Complete information on the current status of people with disabilities can be considered as crucial for creating and directing programs and activities that fall within the jurisdiction of the health, education and social welfare systems (Institute of Medicine, 2012). Initially, an appropriate database is required to gather all necessary and valid information. Population-based registries have an important role in exploring the prevalence, aetiology, risk factors, distribution, frequency and severity of particular developmental disorders or disability in a national or international region. Besides, much of our understanding of a particular disability has come from international population-based registers or resulted from the cooperation of several national registers (Hurley et al., 2015).

Numerous registries have been established worldwide, providing unique resources for international comparisons (Himmelmann et al., 2006; Hurley et al., 2015). Overall, aims of registries include the following: 1) planning of medical, social and educational services, 2) determining etiological understanding and prevention, 3) describing the clinical and demographic profile of disabilities in a particular geographic region, 4) as a resource for future disability research, and 5) as a surveillance program

that monitors trends over time and determines prevalence of the diagnosis within a defined population (Hurley et al., 2015). Similarly, our national registry could be used as an empirical basis for new population research that would be methodologically comparable to other population-based studies.

Generally, needed information is most often related to the following: diagnosis, various personal and family demographic characteristics, basic anamnestic data, current health and functional status of people with disabilities, frequency of health and developmental problems, impairment level, family and personal needs, quality of life, characteristics of the environment, potential for modifications, availability and adequacy of resources, use of services at the level of health, education or social welfare systems, the amount of their costs, and more (Institute of Medicine, 2012). Such information should also be considered from the aspect of public health, which they are an integral part of, as well. Besides, public health surveillance is "the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (German et al., 2001).

Evaluation of medical and other medical-related problems at the level of population, especially the population of people with disabilities, requires some form of surveillance system to ensure efficient and effective monitoring. For these purposes, various data sources can be used. The most common ones include the registers and information systems related to a specific disease or health condition, survey data, and administrative databases or clinical databases, as well.

Information, per se, is necessary, but not sufficient when planning services and counselling with families (Arneson et al., 2009). Therefore, their prioritization, evaluation and use might be more pragmatic (Institute of Medicine, 2011). For example, longitudinal monitoring of the efficiency and effectiveness of different early intervention programs will be available, thus creating the basic infrastructure for extending, modifying, improving and increasing the quality of service support, whether they come from the health, education or social welfare systems.

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Initial steps, basic requirements and general recommendations in the founding process of a registry of people with disabilities

To meet the basic requirements for the successful functioning of a registry, several issues need to be considered in the early phases of the designing process, both theoretically and practically. Setting the concrete, practical and procedural steps should follow the fulfilment of these central requirements.

First, stable funding should support the clearly defined purpose. Secondly, it is important to specify the key terms and inclusive or exclusive criteria precisely. Next, it is crucial to design and implement a standardized format of data collection, as well as to outline an area of data collection geographically. Certainly, data on the general population should be available, related to population growth, the number of live births per birth weight, and perinatal mortality rates. Information on population migration on the observed geographical region should also be included here. Further, the multidisciplinary data content is only achievable through appropriate multidisciplinary team coordination. Generally, the methodology of data collection must be flexible enough. Bearing in mind that collecting large amounts of data increases the risk of their marginal values and questionable quality, a certain readiness to expand and embrace new technologies for secure data collection is a constant demand. In that manner, the data collection system would be relevant and functional. Additionally, the registry would be more adaptable to the changing needs of its users at any time, and for whose needs it was designed in the first (Cans et al., 2004; Newton & Garner, 2002). Nevertheless, data confidentiality and the administrative part must be entrusted to the appropriate and competent services, bearing in mind the sensitivity of the data type (Li et al., 2019).

Regarding the initial steps, it is necessary to establish a framework for organizing, automating and analysing data on aetiology, demographics and functioning. If we ought to systematically and continuously address emerging problems, difficulties, complications and comorbidities for people with disabilities, then this framework should also contain feedback loops, in order to review the changes and update the database. Continuous and real-time reviews can help to identify and eliminate problems before they grow. The aforementioned recommendations can also be considered as basic

guidelines for the more practical service of newly established registries. Registries should also serve as a central database or a tool to assist and promote the future studying of various disabilities throughout the lifespan.

Challenges and alternative solutions in a national database or registry founding process

Various challenges of a methodological, organizational, legal or technical nature may be encountered during the registry founding process. Population size, poor inter-institutional cooperation, decentralization of health and social welfare systems, including separate and fragmented health care, social support and school services, are the most common barriers or obstacles listed in the literature (Hurley et al., 2011; Paneth et al., 2006). In summary, it is most likely that some registers or databases already exist, such as administrative, local medical or clinical ones. In these circumstances, the first question is how to bridge the gap between planned or intended population-based databases and available databases. One possible solution is to establish first a network of interconnected regional or local registers. These local registers would be the one in direct contact with people with disabilities. As follows, the option of subsequently expanding this registry would be left open. For example, in that way, the Cerebral Palsy Research Registry was established in the United States (Hurley et al., 2011).

Previous studies have initiated the founding of a national registry in our country, too (Demeši Drljan, 2011; Milićević, 2016). It was explained that the national registry was a basic prerequisite to systematically analyse the current situation and needs of people from this population, in this case, people with cerebral palsy. Moreover, it was concluded that it was the way to systematically organize services and support at the level of population of people with disabilities and their families. Also, services, interventions and programs within the scope of special education and rehabilitation work could be planned in a realistic framework. After all, to gather and provide information for more efficient and effective service planning, the founding of a central database has already been recommended in the literature (Arneson et al., 2009).

However, the registers formed in this manner are not without limitations (Hurley et al., 2011). First, the data are collected from the participants, which include people with disabilities, their caregivers and/or their physician, by

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using a questionnaire. These data are not compared directly with the medical records unless they are alternatively integrated. Furthermore, registration is restricted to passive and active voluntary involvement. Methodologically speaking, due to these restrictions, this kind of population-based registry is not primarily epidemiologically based, which should be kept in mind.

The use of administrative databases is an alternative solution when a central registry is not achievable or practical. It is possible to conduct a comparative analysis of several different administrative databases nationwide. For example, the birth records and death certificates for a defined period could be compared with hospital discharge lists, as well as with emergency services, ambulances and home visits data, including the data from the relevant departments for people with disabilities or special needs (Li et al., 2019). When planning data collection at the population level, the cost-effectiveness is the main benefit of this approach to the problems. As previously explained, available data might be extracted from the administrative databases that had been already existing (Li et al., 2019). It is noteworthy that these administrative databases cover large populations and geographical areas over a certain period. Additionally, by their design and purpose, they store a sufficient amount of general information that can be further used for research purposes.

On the other hand, the proposed solution has some limitations, as well (Li et al., 2019). First, there is a certain inability to identify potential environmental impact accurately. Consequently, the generalization of the results obtained in this way is questionable outside the explored geographical area due to differences in population structures and clinical practices of the targeted population. Next, subsequent qualitative data verification is not practical. Uncertainty in diagnostics, the misclassifying tendency, multiple sources of data, co-occurring technical errors, as well as different coding practices, are just some of the additional limitations. The aforementioned includes the consequences related to inconsistencies in insurance and billing options, such as unused or non-funded services. Similarly, the inconsistency of the data on the functional characteristics of the same patient at different examinations between different providers might be expected. The need to check the validity of all sources of information is mentioned in some previous reports, especially when it comes to the epidemiology of specific health problems (Dan, 2015; Institute of Medicine, 2012). As explained, hospitals are a part of the health-care system. They collect data on diagnoses, procedures, complications, and associated conditions, primarily for

financial and practical reasons, not for scientific or research purposes. The insufficient precision of information is a result of the lack of standardization or incompletely implemented standardization of data collection, but also because of identification or assessment problems (Dan, 2015). Besides, the coding practice is originally designed for optimizing billing (Wagner et al., 2015). Health professionals are more likely to use the Diagnostic and Statistical Manual classification system (DSM) in their every work compared to the International Classification of Disease, 9th revision (ICD-9). This represents a methodological limitation because an exclusive use of administrative data may lead to bias or predisposition towards a single set of data, due to lack of validation based on the medical records or medical history (Wagner et al., 2015). Secondly, differences between the two coding systems may contribute to discrepancies in diagnosing comorbidities or associated conditions, with difficulties in re-coding the collected data from one coding system to another (Wagner et al., 2015)

Therefore, it is necessary to improve standardization and validate coding algorithms as a way of verifying medical data. In other words, after the two-way cooperation between the health-care services and the health-care users is established through the administrative database, further use of data for research and epidemiological purposes may be justified (Dan, 2015). Measures and initiatives should be defined and used to determine which indicators will be used to track the strategy implementation (Simeunović, 2015). Also, it can be useful to establish the procedure for the process of collecting and verifying data more precisely, as well.

Concluding remarks

The initiative to found a registry of people with disabilities is undoubtedly an important current topic with the unresolved issue of both theoretical and practical relevance. The benefits of having this type of database or registry of people with disabilities, methodological obstacles in their founding and some of the overcoming strategies were addressed. As a conclusion, this paper calls for the initiation of a national registry or database formation.

In this paper, several possible benefits are identified. Summarization of the clinical and demographic profile of disabilities at a particular geographic region and provision of support for overcoming systemic barriers are underlined. Overall, expected outcome refers to the improvement of health policy, special

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services recognition and rendering, customized programs and regulated management of available resources. On the other hand, methodological barriers are primarily related to the lack of standardization in case-by-case assessments and the consequently questionable accuracy of diagnostic and anamnestic data. Errors are caused, among other things, by the use of various definitions, classifications, and coding algorithms. Thus, the quality of data obtained from systems founded for administrative and financial purposes may differ significantly from the data collected by the analysis of certain internal databases of health and educational or social welfare institutions.

Future research should incorporate an examination of the feasibility and possibilities of implementing different models of founding a national or regional database or registry of people with disabilities. Emphasis should be on the selection of appropriate strategies, and on the examination of available data sources and methodological challenges of collecting data. Several issues and procedural steps should be reviewed, including the integration of available information systems, the verification of data standards, and the electronic exchange of health data.

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PROCES OSNIVANJA REGISTRA OSOBA SA INVALIDITETOM – METODOLOŠKI IZAZOVI I STRATEGIJE PREVAZILAŽENJA

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Sažetak

Prednosti baze podataka ili registra osoba sa invaliditetom, metodološke prepreke i strategije njihovog prevazilaženja su izdvojene u ovoj aktuelnoj temi. Prednosti uključuju rezimiranje kliničkog i demografskog profila ometenosti na određenom geografskom području, pružanje podrške za prevazilaženje sistemskih barijera, poboljšanje zdravstvene politike, prepoznavanje i pružanje posebnih usluga, prilagođenih programa, kao i regulisanje upravljanja raspoloživim resursima. Metodološke prepreke se odnose na nedostatak standardizacije u procenama pojedinačnih slučajeva i posledično upitnu tačnost dijagnostičkih i anamnestičkih podataka. Treba obratiti pažnju i na upotrebu različitih definicija, klasifikacija i algoritama kodiranja. Kvalitet podataka dobijenih iz sistema koji su primarno osnovani u administrativne i finansijske svrhe može se značajno razlikovati od podataka prikupljenih analizom internih baza podataka zdravstvenih i obrazovnih ustanova i ustanova socijalne zaštite. Kao zaključak, predstavljeni su i navedeni ključni koraci za proces inicijacije osnivanj nacionalne ili regionalne baze podataka ili registra osoba sa invaliditetom. Oni bi trebalo da uključe analizu primene različitih modela osnivanja, izbor odgovarajućih strategija, ispitivanje dostupnih izvora podataka i informacionih sistema, verifikaciju standarda podataka i metodologije prikupljanja podataka, uključujući elektronsku razmenu podataka povezanih sa zdravljem.

Ključne reči: baza podataka, populaciono istraživanje, ometenost, istraživanje, Srbija