



Derleme / Review

A Current View of Data Collection on People with Disabilities in Türkiye

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Abstract

Social policies are increasing worldwide, and collecting data on disadvantaged groups is becoming critical. Evaluating the data collection process for people with disabilities (PWD), who constitute a significant part of society, is critical in terms of both identifying their needs healthily and determining the effectiveness of social policies accurately. Therefore, this article aims to examine the data collection process regarding PWD in Türkiye in the light of existing literature and current developments. Disability and Aging Statistical Bulletin, which is updated with data regularly collected by the Ministry of Family and Social Services every year and presented with comprehensive content, is considered important in describing the current situation for PWD. Statistical bulletins, which include specific data in the most basic areas, such as education and employment, are essential for social policies. This article discusses the data collection process for PWD in Türkiye, including policy recommendations and implications.

Keywords: Disability, Data collection, Social policy, Disadvantaged groups.

Türkiye'de Engelli Bireylere Yönelik Veri Toplama Sürecine Güncel Bir Bakış

Öz

Dünya ile paralel olarak Türkiye'de de sosyal politikaların arttığı görülmekte ve dezavantajlı gruplara ilişkin veri toplama süreci önemli hale gelmektedir. Toplumun önemli bir parçasını oluşturan ve yaşadığı sorunlar açısından sosyal politikaya en fazla ihtiyaç duyan gruplar arasında yer alan engelli bireylere yönelik veri toplama sürecinin değerlendirilmesi, hem ihtiyaçların tespitinin sağlıklı bir şekilde yapılması hem de sosyal politikaların etkililiğinin doğru bir şekilde tespit edilmesi açısından büyük bir öneme sahiptir. Dolayısıyla, bu makale Türkiye'de engelli bireylere ilişkin veri toplama sürecinin var olan literatür ve güncel gelişmeler ışığında incelenmesini amaçlamaktadır. Her yıl Aile ve Sosyal Hizmetler Bakanlığı tarafından düzenli olarak toplanan veriler ile güncelleştirilerek geniş bir içerikle sunulan Engelli ve Yaşlı İstatistik Bülteni engelli bireylere yönelik var olan durumun betimlenmesinde önemli görülmektedir. Eğitim ve istihdam gibi en temel alanlarda spesifik verilerin dahil edildiği istatistik bültenleri sosyal politikalar açısından elzemdir. Bu makalede Türkiye'de engellilere yönelik veri toplama süreci, politika önerileri ve çıkarımlar açısından tartışılmıştır.

Anahtar Kelimeler: Engellilik, Veri toplama, Sosyal politika, Dezavantajlı gruplar.

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1. INTRODUCTION

Invisible groups are becoming increasingly significant in the world. Ignoring these groups in society means ignoring a significant part of society. According to literature, these groups are referred to as socially excluded groups. Social exclusion cannot be attributed to one reason so that various reasons may lead to social exclusion. At the same time, invisible groups are generally among the most vulnerable groups (Akter, 2012). In order to make these groups visible, it is necessary to understand their lives and ensure the correct flow of information because it is not possible to take any precautions and policy interventions, let alone the decline in their living standards, while they remain invisible. Considering that each invisible group has different dynamics, evaluations for these groups should be handled separately. People with disabilities (PWD) are among the most invisible and vulnerable groups facing numerous challenges (Conte, 2020). Thus, as the first step in solving problems related to PWD, it is necessary to collect sufficient data about their lives, and the fact that countries follow different policies on this issue makes country-specific evaluations essential. In this context, although 16% of the global population lives with some form of disability, the fact that clinical trials are under-recorded and unreported creates health inequalities for this specific group (Cunningham et al., 2025). Moreover, awareness for organizations of persons with disabilities varies greatly across countries. A study conducted by Bank et al. (2024) analyzing data from organizations for persons with disabilities in nine low- and middle-income countries revealed that about one-third of individuals with disabilities were aware of these organizations. The level of awareness varied significantly, ranging from 12% in Lesotho to 73% in the Maldives. This shows that even if disabled people live in countries with similar development levels, their outcomes vary significantly. On the other hand, a study by Mitra et al. (2022) found that only 31% of 734 datasets from 133 low- and middle-income countries collected between 2009 and 2018 included at least one disability-related question. Most of these datasets asked, "Do you have a disability?". These findings were evaluated as insufficient data collection to reach internationally comparable data. Therefore, there is a need to improve data collection processes.

PWD are an integral part of society. Nonetheless, they often face exclusion and many other challenges. For example, PWD experience discrimination in participation in employment, and this is well-documented by many different studies around the world (Daly and Whelan, 2021). Quota practice, one of the most common practices to increase employment of people with disabilities, is considered an outdated social welfare policy tool, so it is clear that new policies are needed (Revillard, 2023). It cannot be assumed that PWD's needs remain constant in today's changing conditions. The multiplicity of opportunities with the rapid development of technology is an essential indicator that the opportunities for disadvantaged groups such as PWD can be increased. While opportunities are increasing, the resources allocated to social policies are limited, so implementing correct practices is necessary to solve the problems. Thus, data collection has an important place in determining the need to develop social policies and appropriately implement the right policies.

In parallel with the decline in the working-age population, especially in European countries, PWD have become much more significant in many areas, such as employment, and it is reported that research on PWD are more critical than ever (Vornholt et al., 2018). Therefore, collecting data on PWD is of greater importance for countries. The equality gap for PWD is still high (Lysaght et al., 2015), so their motivation and experiences are not encouraging them to participate in different fields so they can contribute effectively. Due to the barriers that PWD are exposed to, an additional effect that limits them occurs and prevents them from being active in different areas (Waltz and Schippers, 2021). Social policies regarding PWD can majorly impact their daily lives (Priestley and Grammenos, 2021). Data collection is critical to appropriately directing these policies. Moreover, PWD's experiences and, therefore, their problem situations

differ depending on the type of disability (Sciulli et al., 2012). The data collection process is expected to be richer for PWD, who have many different types of disabilities compared to other disadvantaged groups. PWD are at risk of marginalization, social isolation, and poverty (Alexiadou, 2022). PWD continue to experience these challenges for both genders (Golata, 2021). Even if PWD are employed, they can find lower-skilled and part-time jobs, so it may be helpful to look at it from a dynamic perspective by taking into account more specific indicators when collecting data (Lejeune, 2023). There are concerns that little data is collected, especially on young PWD (Magrin et al., 2019). Therefore, the necessity of data collection to focus on different age groups and different dynamics of the subject is reported in the literature, and the situation of countries regarding data collection needs to be addressed.

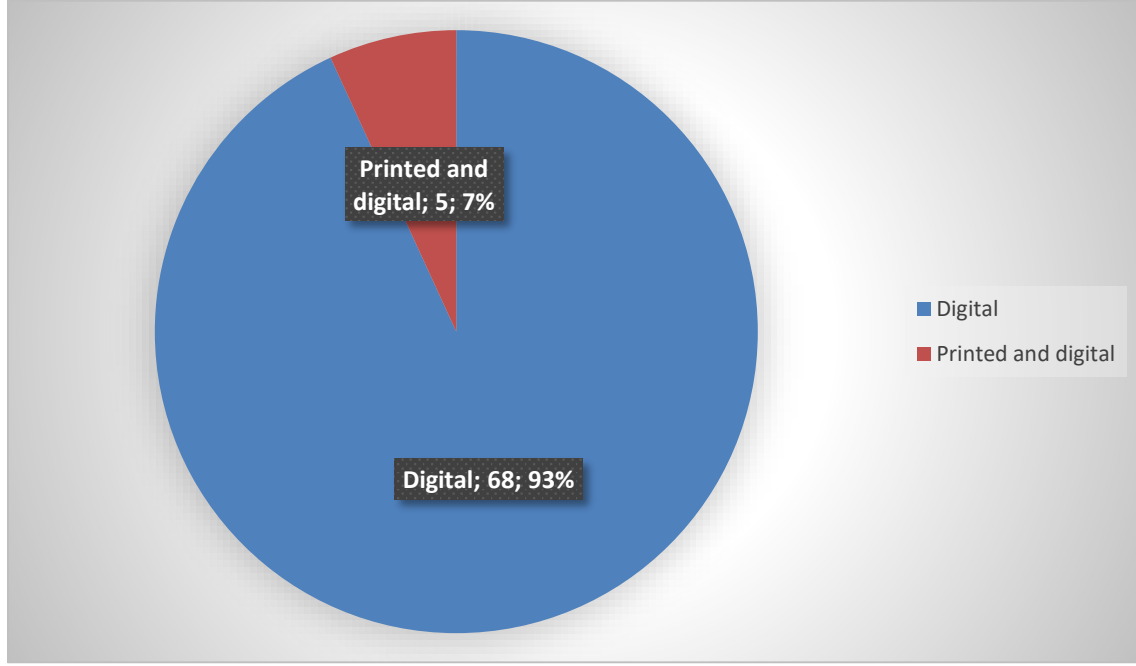
The fact that PWD continue to experience problems despite being considered the world's largest minority group is an important issue (Khan et al., 2019) and shows that social policies are needed. According to the social investment perspective, better outcomes can be achieved as countries provide opportunities to these groups through social policies (Van der Zwan and de Beer, 2021). This suggests the value of investment in social policies. In this respect, monitoring is critical in developing and implementing correct social policies and revising the implemented social policies by evaluating their effectiveness. This can only be achieved by collecting sufficient data in the necessary areas. The fact that PWD are a disadvantaged group requires that collected data be obtained, evaluated, and published and policies developed sensitively. Geiger et al. (2017) suggest that future research should address the effectiveness of social policies in solving the problems experienced by PWD. Nevertheless, according to the Ministry of Family and Social Services (2023) statistical bulletin, the employment gap between PWD and others in Türkiye is relatively large. Therefore, it may be helpful to examine data collection before creating social policies to produce more effective social policies with sufficient data. On the other hand, Geiger et al. (2017) highlight that policymakers need to see successful policies on PWD in other countries. Examining data collection on PWD in Türkiye, which has started to collect data regularly and in large areas, is also crucial in revealing the functional systems and giving positive examples to other countries. Thus, this study aims to investigate the current data collection status on people with disabilities in Türkiye. For this purpose, keywords were first determined by considering the literature and existing terminology. While the keywords "veri", "bilgi", "engelli" and "engellilik" were used for the Turkish literature review, the keywords "data", "information", "disabled" and "disability" were used for the English literature review. These keywords were searched in Google Scholar and Science Direct databases between May 3, 2024, and May 12, 2024.

2. DATA COLLECTION ON PEOPLE WITH DISABILITIES IN TÜRKİYE

It is important to analyze the general characteristics of the publications released by the General Directorate of Services for Persons with Disabilities and the Elderly. This directorate, which operates under the Ministry of Family and Social Services, is directly involved with individuals with disabilities. Examining these publications can provide a better understanding of current trends. Publications on disability, other than the regularly published Disability and Aging Statistical Bulletin, are presented in the publication/resource section of the General Directorate of Services for Persons with Disabilities and the Elderly's website (Ministry of Family and Social Services, 2025). In the document review made by the author on 12.04.2025, it was seen that the publications were between 2008 and 2023, and a total of 73 publications on the subject of disability were reached. Versions of the same publication in different languages and publications not specific to Türkiye were excluded. In the document review, the publication type, category, year, and page number of information given in the publications were digitized and shown with figures and tables.

Digital-only publications cover the majority of publications with 93%. Publications published in both printed and digital formats are at a low level, with 7%. The types of publications on disability by the General Directorate of Services for Persons with Disabilities and the Elderly can be seen in Figure 1.

Figure 1: The Distribution of Publication Types on Disability by the General Directorate of Services for Persons with Disabilities and the Elderly



The most published category is guide, with 28.76%. E-bulletin comes second with 24.65%. There are 15 different publication categories. The least frequently published ones are the policy paper, project book, and conference proceedings, with only one of each published. The distribution of publication categories on disability by the General Directorate of Services for Persons with Disabilities and the Elderly can be seen in Table 1.

Table 1: The distribution of publication categories on disability by the General Directorate of Services for Persons with Disabilities and the Elderly

Publication categories	f	%
Analysis	3	4.10
Brochure	2	2.73
E-bulletin	18	24.65
Family training set	4	5.47
Guide	21	28.76
Handbook	4	5.47
National action plan	4	5.47
Newsletter	2	2.73

Policy paper	1	1.36
Project book	1	1.36
Proceedings	1	1.36
Report	6	8.21
Research	4	5.47
Symposium book	1	1.36
Workshop report	1	1.36

Most publications were published in 2020, with 21.91%. The years 2021 and 2014 come second with 12.32%. In recent years, more publications have been published than in previous years. The distribution of publication years on disability by the General Directorate of Services for Persons with Disabilities and the Elderly can be seen in Table 2.

Table 2: The Distribution of Publication Years on Disability by the General Directorate of Services for Persons with Disabilities and the Elderly

Publication years	f	%
2023	3	4.10
2022	5	6.84
2021	9	12.32
2020	16	21.91
2019	6	8.21
2018	1	1.36
2017	2	2.73
2016	5	6.84
2015	3	4.10
2014	9	12.32
2013	4	5.47
2012	1	1.36
2011	4	5.47
2010	4	5.47
2008	1	1.36

The publications were mostly in the 0-49 page numbers range, with 38.35%. The 50-99 page numbers range comes second with 35.61%. Therefore, while the publications were mostly in the 0-100 page range, only 26% were published with 100 or more pages. The distribution of publications' page numbers on disability by the General Directorate of Services for Persons with Disabilities and the Elderly can be seen in Table 3.

Table 3: The Distribution of Publications' Page Numbers on Disability by the General Directorate of Services for Persons with Disabilities and the Elderly

Publications' page numbers	f	%
0-49	28	38.35
50-99	26	35.61
100-149	7	9.58
150-199	6	8.21
200 and above	6	8.21

Services for PWD in Türkiye were first carried out by the Prime Ministry Department of the Administration of the Disabled. Later, the General Directorate of Disabled and Elderly Services was established within the Ministry of Family and Social Services (Bulut, 2020). This is not specific to PWD as a disadvantaged group. In order to produce effective work to solve the problems faced by disadvantaged groups, different directorates for different disadvantaged groups have been established within the Ministry of Family and Social Services (Çevik and Özkul, 2022; Durğun and Merde, 2023). In this respect, the General Directorate of Disabled and Elderly Services continues to collect data and actively publish and create social policies. Within the scope of the protocol made between the Turkish Statistical Institute and the General Directorate of Disabled and Elderly Services in 2010, research on the problems and expectations of disabled people was conducted for the first time in Türkiye for disabled people registered in the National Disabled People Database (Şen, 2018). Later, the Ministry of Family and Social Services carried out large-scale data collection, publication, and social policy development and implementation processes. Most importantly, the Ministry of Family and Social Services has started to publish the "Disability and Aging Statistical Bulletin" regularly in certain months every year (Çakır, 2021). This suggests that important steps have been taken to systematize the data collection process on PWD in Türkiye.

"Disability and Aging Statistical Bulletin" publishes specific information regarding PWD under general topics such as employment, education, social benefits, care service, and accessibility (The Ministry of Family and Social Services, 2023). Creating these bulletins, published by the Ministry in recent years, with systematic, unchanging, and comprehensive content is essential in revealing the change, identifying needs, and examining the effectiveness of the implemented policies. For example, when looking at the bulletins published by the Ministry of Family and Social Services in the last four years, it is seen that they have specific and detailed content under the same subject headings. Data is re-collected for each bulletin and presented together with visual material. If data were collected every few years, no output would emerge regarding the effectiveness of the policies made, and therefore, policies would be implemented and evaluated without foresight. On the other hand, if data were published every few years despite being collected continuously, the data available to policymakers would not contribute to the scientific literature nor provide sufficient evidence for researchers and experts to evaluate. Considering

that the largest capital studies on PWD belong to the public, the importance of data collection and publishing processes carried out by the state increases even more. Moreover, considering that institutional care and social assistance related to PWD are under state control and monitoring, the process of collecting and publishing data directly on public services can be achieved thanks to the new data published in the "Disability and Aging Statistical Bulletin", which is collected regularly every year. This bulletin paints a detailed picture of the situation regarding PWD in Türkiye rather than just a superficial description. Furthermore, the results of ongoing social policies such as quota implementation and the number of people benefiting are regularly included in this bulletin. This bulletin includes collecting functional and regular data and presenting this data in terms of determining social policy needs, explaining social policy practices, and evaluating the implemented social policies.

In the world, PWD experience a considerable stigma regardless of their culture (Jansen-van Vuuren and Aldersey, 2020). In other words, there is a prevalent issue of stigma towards PWD. In this regard, PWD, both young and old, can be subject to social exclusion (Ditchman et al., 2016). At this point, collecting data about PWD from all age groups can reveal crucial implications because every country has different populations and problem situations. Examining each age group separately according to their specific situations may be helpful in the data collection process. In this respect, there are age categories in the statistics regarding PWD collected and published by the Ministry of Family and Social Services, especially in the "Disability and Aging Statistical Bulletin". Moreover, these statistics also include categories for different types of disabilities. Thus, the data collection process regarding PWD in Türkiye is carried out very precisely and allows analysis in terms of intersectionality by considering different categories.

Due to fast-paced changes in the world and Türkiye, it is imperative that countries quickly take action on social policy regarding disadvantaged groups (Urvaylıoğlu and Gedik, 2021). In this sense, it is crucial to gather data on a regular basis. Regular data collection is needed to make both short-term and long-term plans and to measure their effects. At the same time, it is crucial to collect data at short intervals to monitor and control the dynamics that can change negatively at any time for disadvantaged groups such as PWD. Unrevised policies may not be effective in practice if data is collected infrequently or at long intervals. That is why, thanks to the data regarding PWD that the Ministry of Family and Social Services collects regularly every year, even the slightest change can be noticed and intervened by policymakers quickly.

Smythe (2020) suggests that families are often responsible for meeting the needs of PWD because they require assistance from their immediate surroundings. Families are both impacted by PWD and impact PWD. Thus, social policies should address the needs of PWD as well as their families. Regarding data collection, it is not enough to only include PWD, so collecting data in a multidimensional manner can offer significant benefits. From this point of view, collecting data on the immediate surroundings of PWD can be beneficial. At this point, the Ministry of Family and Social Services attaches importance to collecting data about the PWD's immediate surroundings, especially family members. For example, data on female-insured women with severely disabled children is collected and published in the "Disability and Aging Statistical Bulletin" by the Ministry of Family and Social Services (2023). From the perspective of the social disability model, data collection is carried out for all areas of society, especially education and employment, with the view that there is no obstacle for PWD to be active in every field. Contrary to the medical model of disability, it is desired to establish the understanding that PWD can show themselves in a functional way in every field, and it is observed that policies are being developed in Türkiye in the light of the data collected in this direction.

3. CONCLUSION

The importance of social policy has increased worldwide, and parallel to this, the data collection process has become more critical. Although the needs of disadvantaged groups, which are the focus of social policies, have changed from past to present, they continue with the same urgency and even become more complex day by day, revealing the necessity of new policies. Since each country's resources, priorities, and population characteristics differ, the focus of social policies changes in this direction, and therefore, the areas where the data collection process takes place differ. On the other hand, with globalization, the shrinking of borders between countries and the similarities in the problems faced by disadvantaged groups such as PWD around the world are apparent. Therefore, it has become essential to develop a universal understanding of the focus of social policies regarding PWD and data collection in this direction. It would be wrong for policymakers to make evaluations only country-specific or completely independent of the country's characteristics regarding data collection with a narrow understanding. In this regard, the first step is collecting extensive data, including the most basic areas, such as education and employment, to identify needs. For Türkiye, the Ministry of Family and Social Services collects and publishes comprehensive data on PWD. The second step is to collect and publish comprehensive data at regular and frequent intervals. The Ministry of Family and Social Services ensures this with the "Disability and Aging Statistical Bulletin," which is published every year. Therefore, the data collection process on PWD in Türkiye is carried out regularly and frequently. Thus, important arguments regarding PWD are revealed in determining the needs for social policies and evaluating the implemented social policies.

In current data collection systems, PWD living in urban areas may be preferred over PWD living in rural areas because they are more accessible. However, it is important to include PWD living in rural areas at least as much as PWD living in urban areas to ensure the generalizability of the data. It would be helpful to include PWD with different characteristics in studies to diversify the existing data.

Analyzing only Turkish official sources constitutes the limitation of this study. In future studies, including unofficial sources in the analysis and evaluating them together with official sources may provide important implications. It may be useful for future studies to compare data collection processes across countries. It is important in terms of policy recommendations to evaluate the data collection and dissemination processes of different institutions collecting data on disability together.

The data collection process on PWD carried out by the public in Türkiye may benefit from the support of nongovernmental and civil society organizations. In addition, it is important to encourage PWD to share data in order to generalize the information processed in databases. For PWD to become a visible group, effective social policies must be implemented based on the issues identified through collected data. The fact that data collection processes are managed by ministries in comprehensive bulletins for Türkiye results in a frequent and regular data collection process.

Çıkar Çatışması

Yazarlar açısından ya da üçüncü taraflar açısından çalışmadan kaynaklı çıkar çatışması bulunmamaktadır.

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