

Report

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Access to health services for persons with disabilities in the EU: Review and Commentary

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Executive Summary: Access to health services for persons with disabilities in the EU: Review and Commentary

Aim

The aim of this report was to review the existing literature on key issues for people with disabilities while accessing healthcare services, as well as differences in access to healthcare between people with and without disabilities.

Barriers are covered in order to highlight the obstacles faced by people with disabilities as they seek to access healthcare. The report also covers a commentary on the challenges and implications faced by health care providers and professionals with regards to access to healthcare services for people with disabilities.

Methodology

In order to conduct a comprehensive analysis, the desk-based research of reports and articles (mainly from Europe) was undertaken. Findings are based on evaluated initiatives and existing services and experiences, although new trends are also mentioned.

The findings and key points

This review highlighted significant barriers, as well as initiatives aimed at improving access to healthcare services for people with disabilities. Providing good access to health for people with disabilities will ensure that their rights are met and help in achieving good health, which will also back the effort in reaching universal health coverage, as will enable people to experience better health, productivity and with it, less poverty.

Introduction

Access to healthcare is a basic human right¹ and one of the fundamental principles of European health systems, together with safety, quality, and equity.² Availability, affordability, relevance and physical accessibility and approachability of services and their acceptability of service users are dimensions which shape access to healthcare.³ In this respect, access to healthcare is defined ‘as the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care’⁴ highlighting the dynamic between the embodied characteristics, social environment and the specifics of the healthcare systems, providers and users.

The report on Inequalities in access to healthcare⁵, measured inequalities in access to healthcare in 35 European countries, with the overall conclusion being that, while there is recognized improvement in access to healthcare, significant inequalities still persist, both between countries, and EU population, specifically vulnerable groups, who face multiple obstacles in receiving the care they need. The key findings can be summarized as: public spending on healthcare varies significantly between countries; underfunded healthcare systems perform worse than EU average with regard to access to healthcare; there is still a high percent of population not covered by the statutory health systems; high out-of-pocket payments; the supply of health services is inadequate in many countries (especially in rural areas); waiting lists are an issue in a large majority of EU countries; the growth in voluntary and occupational health insurance may exacerbate inequalities; several population groups (the ones with lower income, women, minorities, migrants) have significant difficulties in accessing healthcare services.

There is international evidence that suggests that people with disabilities face barriers when accessing needed health services and experience poorer access to healthcare compared to the general population.⁶ People with disabilities often report that their needs are not understood, that they are not understood when asking for help, that they are perceived as

¹ Universal Declaration of Human Rights.

² Council of the EU, Council conclusions on Common values and principles in the EU Health Systems, 2006.

³ Levesque et al. Patient-centered access to health care: conceptualizing access at the interface of health systems and populations, 2013.

⁴ Ibid, p.4.

⁵ EU Commission - Baeten R Et al. Inequalities in access to healthcare, A study on national policies, 2018.

⁶ WHO, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>, seen December 2019.; Gibson J. & O'Connor R., Access to health care for disabled people, a systematic review, 2010.; Popplewell et al. How do adults with physical disability experience primary care? A nationwide cross-sectorial survey of access among patients in England, 2014.; Rotarou ES & Sakellariou D. Inequalities in access to health care for people with disabilities in Chile: the limits of universal health coverage, 2017.

patients of low priority due to their pre-existing conditions, that staff is not equipped with skills to properly deal with their needs, and that they face barriers while accessing services.⁷

The available data suggest that people with disabilities may be less likely to be treated as effectively and in a timely manner compared to people without disabilities.⁸ A systematic review of the information with regards to access to healthcare for people with disabilities found that ‘disabled people are restricted in accessing healthcare and report less satisfaction’.⁹ Difficulties in accessing healthcare can be caused by a range of barriers, some of them mentioned above, including lack of transport, inaccessible buildings, and attitudinal barriers such as lack of awareness and skills by the healthcare professionals.¹⁰

Access to healthcare can be also observed not just through the lenses of physically accessible services, rather also as ‘gaining access’ where the services is successfully used.¹¹ In this way, the access is defined as ‘entry (first contact) healthcare’ which are particularly important when considering access issues, and are seen as the primary point through which people may ‘gain access’ to secondary of ‘continuing’ health services.¹² The ‘continuing healthcare’ is usually provided on referral from a health professional, which considering the long-term health problems people with disabilities are facing, they are more likely to require these services when compared to people without disabilities.¹³

With an estimated over a billion people living with some form of disability,¹⁴ the provision of health care for people with disabilities represents a significant and largely overlooked challenge. One in seven people experience disability in the world.¹⁵ The World Health Organization (WHO) states that “people with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities.”¹⁶

⁷ Levesque et al. Patient-centered access to health care: conceptualizing access at the interface of health systems and populations, 2013.; Drainoni et al. Cross-disability experiences of barriers of health-care access: consumer perspectives, 2006.; Read et al. Being a disabled patient: negotiating the social practices of hospitals in England, 2018.

⁸ Levesque et al. Patient-centered access to health care: conceptualizing access at the interface of health systems and populations, 2013.

⁹ Ibid, p.21.

¹⁰ Ibid & Drainoni et al. Cross-disability experiences of barriers of health-care access: consumer perspectives, 2006.;

¹¹ Gulliford et al. Access to Health Care: Report of a scoping exercise for the National Coordinating Centre for NHS Services Delivery and Organization R&D, 2001.

¹² Ibid.

¹³ Ibid.

¹⁴ WHO, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>, seen December 2019.

¹⁵ WHO. World report on disability, 2011.

¹⁶ Ibid.

Furthermore, the rates of disability are increasing in part due to ageing populations and an increase in chronic health conditions.¹⁷ A disabled person is twice as likely to find healthcare providers' skills and facilities adequate, three times more likely to be denied healthcare and four times more likely to be treated badly in the healthcare system.¹⁸ The relationship between disability and health is complex one, as they are interlinked and are overlapping. With regards to defining disability, a wide range of definitions are used, but the most prevailing one is that of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that "Persons with disabilities include those who have a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".¹⁹

People with disabilities are often the group which is on the marginalized position in society, being more vulnerable to poor health, due to poverty and disadvantageous living conditions,²⁰ which shows that on average people with disabilities will have poorer health than people without disabilities.²¹ Overall, people with disabilities may have a greater need for healthcare services, both due to their impairment and their vulnerability towards the poor health.

Challenges they are facing in accessing healthcare services, either with transport in accessing services, or stigma and discrimination at the point of care, can discourage people with disabilities in reaching out when in need of health care services.²² This can also be said for the skills and experience of healthcare professionals which may be inadequate in order to provide quality service.²³

It has been long overdue with regards to addressing access of people with disabilities to healthcare services, which may have profound implications for them and for a society as a whole. The CRPD specifically states that people with disabilities must have access to general and specialist healthcare (articles 25 and 26), and so exclusion from services will be an infringement on human rights since this convention has been ratified by more than 170

¹⁷ WHO, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>, seen December 2019.

¹⁸ WHO, Infographics, <https://www.who.int/disabilities/infographic/en/> seen December 2019.

¹⁹ UN. Convention on the Rights of Persons with Disabilities, 2006.

²⁰ Banks et al. Poverty and disability in low and middle income countries: A systematic review. 2017.

²¹ WHO. World report on disability, 2011.

²² Bright & Kuper, A systematic review of Access to General Healthcare Services for People with Disabilities in low and Middle Income Countries, 2018.

²³ Ibid.

countries.²⁴ Article 9 (Accessibility) outlines the measures to be taken to ensure that persons with disabilities have access, on an equal basis with others, the physical environment, transport, information and communications (including information and communications technologies and systems) and other facilities and services open or provided to the public by both State and non-state actors in both urban and rural areas. However, despite the importance of this issues, access to healthcare among peoples with disabilities has received little attention in research. Cross—country comparisons of health and social care systems are rare.²⁵ Those that exist are mainly addressing health care expenses,²⁶ or with regards to different health care schemes.²⁷

Method

Aim

The aim of this report was to review the existing literature on key issues for people with disabilities while accessing healthcare services, as well as differences in access to healthcare between people with and without disabilities.

Barriers are covered in order to highlight the obstacles faced by people with disabilities as they seek to access healthcare. The report also covers a commentary on the challenges and implications faced by health care providers and professionals with regards to access to healthcare services for people with disabilities.

The disparities in unmet healthcare needs of people with disabilities stand as a stark remainder of the work that must be done to improve the access to care services. People with disabilities experience worse access to healthcare services, with transportation, communication and information barriers, cost and long waiting lists being some of the barriers. These findings are particularly worrying as they illustrate that a section of the population, who may have higher healthcare needs, faces increased barriers in accessing services.

²⁴ UN. Convention on the Rights of Persons with Disabilities, 2006.

²⁵ Bien et al. Disable older people's use of health and social care services and their unmet care needs in six European countries, 2013.

²⁶ Lehner T., et al. Review: health care utilization and costs of elderly persons with multiple chronic conditions, 2011.

²⁷ Landauer M., et al. Long-term care benefits and services in Europe, 2009.

Understanding disability

It has recently been estimated that 15-19% of the world's population are disabled.²⁸ The number of people who experience disability is expected to rise as the population ages, as well as with the chronic health conditions.²⁹ Disability disproportionately affects women, older people and poor people, and people with disability faces widespread barriers in accessing services, as is healthcare, especially with respect to medical care, therapy and assistive technologies. The barriers can be the effects of the inadequate legislation, policies and strategies, the lack of service provision, problems with delivery of services, a lack of awareness and understanding about disability, negative attitudes and discrimination, lack of accessibility, lack of participation of people with disabilities in decisions which directly affect their lives. These are also related to difficulties some people with disabilities have in expressing their voice and opinions, receive and convey the information. These barriers contribute to disadvantages people with disabilities experience, particularly in developing countries, where higher rates of poverty and lower rates of education place them in more vulnerable position, compared to people without disabilities.³⁰

There is extensive evidence from around the world to suggest that risk of many health conditions and impairments associated with disability increases with age and socio-economic position.³¹ Based on the World Health Survey³² showed that the overall prevalence of disability was significantly greater in poorer countries and in countries with greater levels of income inequality, with prevalence rates for disability higher for women. Based on the WHS data, the overall and median within country prevalence of disability among adults across 29 European countries was 12%, rising from 4% among adults aged 18-39, through 12% among adults aged 40-59 to 25% among adults aged 60 or more. The prevalence of disability was higher among women than men in 27 of these 29 countries. Increased rates of disability were also associated with poorer national wealth, increased within-country income inequality, female gender and lower within-country socio-economic position.

²⁸ WHO. World report on disability, 2011.

²⁹ WHO Global Disability Action Plan – 2014-2021.

³⁰ Ibid.

³¹ She P & Livermore GA. Material hardship, poverty and disability among working-age adults, 2007. Spencer NJ. Poverty and child health, 2000. Blackburn C Et al. Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: Secondary Analysis of the Family Resources Survey, 2010. Emerson E, Household deprivation, neighborhood deprivation, ethnicity and the prevalence of intellectual and developmental disabilities, 2010.

³² WHO. <https://www.who.int/healthinfo/survey/en/>

As mentioned previously, there is also extensive evidence that people with disabilities experience significantly poorer health outcomes compared to people without disabilities. Based on the fact that people with disabilities by definition must have a health condition or impairment, a degree in overall health status is inevitable. As expected most evidence of these inequalities have been generated in high income countries, with few studies from Central and Eastern Europe. However, numerous reports and available data highlighted the disadvantaged social position for disabled people in these parts, with conditions which would be mostly associated with poorer quality of life, health outcomes and life expectancy.

As some health conditions related to disability require extensive health care services, people with disabilities may experience greater vulnerability to preventable secondary conditions, and may require specialist health care services.

Also, the report showed discrepancy in health related services, such as oral health problems, where in 28 of 29 countries age-adjusted rates of oral health was higher for disabled adults than non-disabled adults. In no country was the rate of oral health problems significantly higher among non-disabled people, this being even more prevalent in poorer countries.³³ This only shows that the occurrence and prevalence of many health conditions and impairments is connected to the socio-economic position, being that the higher a person's position is in the social hierarchy, the lower the risk of developing health conditions and impairments associated with disability.³⁴ Additionally, people with disabilities face discrimination with regards to the organizational barriers which prevent them in accessing timely and effective healthcare.

Barriers to health care services for people with disabilities

There have been persistent multi-dimensional barriers to access the health care services across the EU, at individual, provider and health system level.³⁵ Among the reasons, which have been named for the unmet needs and unequal experience, are unaffordable medicines and services, out of pocket payments, waiting times, geographical distance, fragmented care, lack of

³³ Ibid.

³⁴ Emerson E Et al. Health Inequalities and People with Disabilities in Europe: Background Paper 5 for the Social Exclusion, Disadvantage, Vulnerability and Health Inequalities task group supporting the Marmot region review of social determinants of health and the health divide in the EURO region, 2015.

³⁵ Expert Panel on effective ways of investing in Health, Report on Access to Health Services in the EU, 2016.

financial care across the systems, socio-economic disparities,³⁶ which is only exacerbated for people with disabilities.

The reasons for barriers can be found in lower levels of educational attainment, lower income, and employment rate, all of which are associated with lower use of healthcare services.³⁷ The structural disadvantages have also an intersectional dimension which cannot be ignored; for example, various research has shown that women with disabilities are more likely to face barriers in accessing healthcare services than any other group.³⁸

The review of the literature revealed thematically similar barriers across different countries. As an example, the UNAPEI³⁹ report identifies the barriers to equity of care as – poor communication, poor healthcare coordination, insufficient access to health prevention and reduced care, health professionals poorly trained and lack of accessibility. In the paper, in order to fully showcase the barriers people with disabilities are facing, they will be presented with regards to the demand side, i.e. the individual seeking health care services, and the barriers on the supply side, i.e. the health care provision.

While assessing the access to healthcare for people with learning disabilities,⁴⁰ the report found that barriers with respect to the entry (first contact) healthcare were found to be rigorous⁴¹, suggesting that people with learning disabilities may access general practice and dental surgeries less frequently compared to people without disabilities. Again, barriers that were identified were much related to communication difficulties, time constraints and examination difficulties.

The research on the access to continuing care and secondary care showed that studies were mainly dealing with mental health services, with a conclusion that people with learning difficulties had difficulties accessing specialist mental healthcare, with studies on mental health of older people also found significant unmet needs. And although this report was covering, at this point, older studies, there is still a reoccurring theme that much is still needed

³⁶ European Commission, Joint Report on Health Care and Long-Term Care and Fiscal Sustainability, 2016.

³⁷ WHO, World Report on Disability, 2011.

³⁸ Sakellariou D. & Rotarou ES. Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data, 2017.

³⁹ Pour une santé accessible aux personnes handicapées mentales. Paris: Union nationale des associations e parents, de personnes handicapée mentales et de leurs amis; 2013.

⁴⁰ Alborz A. et al. Access to healthcare for people with learning disabilities: mapping the issues and reviewing the evidence, 2005.

⁴¹ Singh, P. Prescription for change: a Mencap report in the role of GPs and carers in the provision of primary care for people with learning disabilities, 1997.

for access to healthcare needs for people with disabilities to be on the level designed by the adopted international policies and guidelines.

Barriers on the demand side

Lack of information on the availability of services

Available research suggests that people with disabilities are often unaware of the healthcare services they can access in the mainstream healthcare centers⁴², despite the fact that people with disabilities have higher need for health care compared to people without disabilities, and there is also a significant difference between people with disabilities in whether they know where they need to go in case they need treatment.⁴³ Signs and notices in health care facilities have been problematic for people with learning disabilities, low literacy levels, or sensory disabilities.

Clarity of information and communication is a recurring theme across the literature. In one qualitative study⁴⁴ the intent was to examine the extent to which patients with intellectual disability and their carers experience discrimination or other barriers in accessing health services, and whether health care experiences have improved over the last decade years. Twenty-nine participants took part in semi-structured interviews, with the conclusion that half of the participants who thought that the patient had been treated unfairly or had been discriminated against by health services. Other barriers included problems with communication, and accessing services because of lack of knowledge of local services and service eligibility issues; lack of support and involvement of carers; and language problems in participants from minority ethnic groups.

Additional expenses to access health care

As people with disabilities often find themselves excluded from the jobs market and with higher living costs, due to their needs, they often cannot pay for health care services out of pocket. In their study, Beatty et al⁴⁵ found that people ‘with the poorest health and with the

⁴² Alborz A. et al. Access to healthcare for people with learning disabilities: mapping the issues and reviewing the evidence, 2005.

⁴³ Ibid.

⁴⁴ Ali et al. Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers, 2013.

⁴⁵ Beatty et al. Access to health care services among people with chronic or disabling conditions: patterns and predictors, 2003.

lowest income were the least likely to receive all health services needed'. The cost associated with the treatment and general access to health care services is regularly named as one of the main obstacles to accessing healthcare services by people with different disabilities and impairments. People with disabilities and their carers often are the group which mostly struggle with poverty due to limited access to employment, being the ones to most likely use the subsidies and various insurance programmes which can mitigate the costs of health care.⁴⁶ However, they are the group which actually needs higher health care services and treatments, which are in many cases related to higher costs. In addition, people with disabilities are impeded with high transportation costs in order to get to the healthcare facility, which also relates to the cost of people accompanying them, and/or have to hire a specialized means of transport, which is an additional cost related to healthcare, that people without disabilities do not encounter.⁴⁷ In the UK,⁴⁸ the largest gap for people with disabilities can be seen in the category of 'unmet need for mental health care due to cost', where people with disabilities were 4.5 to 7.2 times more likely to encounter a problem, as well as in the category 'unmet need due to cost of prescribed medicine' where they were from 3.6 to 5.4 times more likely to face a difficulty.⁴⁹

Limited mobility

Transportation and other issues have been named as a barrier to people with disabilities in accessing healthcare in various research literature.⁵⁰ Mobility related barriers fall in the group on the demand side, as people with disabilities need assistance and additional help in order to get to a healthcare facility, accompanied with the additional costs. This is exacerbated in the rural areas where health centers are often a long distance from where people with disabilities live, and public transport is often inaccessible for them, which requires an alternative model of transport, and with that, costs.⁵¹ Sakellariou and Rotarou⁵² found that people with disabilities in the UK had between 2 and 4 times higher chances of having unmet healthcare needs due to transportation barriers. People with disabilities have more necessities for healthcare services, compared to people without disabilities, and in most cases the availability

⁴⁶ Ibid.

⁴⁷ WHO, Global Disability Action Plan 2014-2021, 2015.

⁴⁸ Sakellariou D. & Rotarou ES. Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data, 2017.

⁴⁹ Ibid, p.3.

⁵⁰ Ibid, p.3.; Gibson J. & O'Connor R., Access to health care for disabled people, a systematic review, 2010.; Drainoni et al. Cross-disability experiences of barriers of health-care access: consumer perspectives, 2006.

⁵¹ Sakellariou D. & Rotarou ES. Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data, 2017.

⁵² Ibid.

of transportation is not adequate, as Read et al.⁵³ argue, hospital transportation is sometimes wheel chair not accessible, or runs on a tight schedule, to accommodate as much people as possible.

Although rural settings are more recognized for their lack of services, particularly specialist services, there have been some cases and studies where the community and overall social cohesion was found to be beneficial for the wellbeing of people with disabilities.⁵⁴ One Scottish study showed better than average use of services such as optician and dental care.⁵⁵ However, specific challenges still remain – as Hussain and Tait⁵⁶ concluded, the parents of children with intellectual disabilities in rural settings experience a lack of information of available support which, along with the limited experience, ‘poor attitudes’ and frequent turnover of healthcare providers are only adding to the feelings of isolation.

Barriers on the supply side/healthcare service provision

Staff attitude

The attitudinal barriers of medical staff and professionals have been extensively reported. Health care providers appear to be insensitive to the needs of people with disabilities, due to the lack of knowledge and/or skills about the needs of people with disabilities, which consequently undermines the desire of people with disabilities to use healthcare services. The negative attitude has been associated with the staffs’ lack of understanding and awareness of the needs and health care conditions of people with disabilities.⁵⁷ People with disabilities often report that they feel their needs are not understood, that they feel not recognized and listened to and that they are perceived as patients with low priority due to their pre-existing condition.⁵⁸ The study on the barriers to accessing cancer services faced by adults with pre-existing disabilities in the UK⁵⁹ found that people with physical disabilities face variety of barriers in accessing cancer services, with the overall conclusion from the data gathered, that participants

⁵³ Read et al. Being a disabled patient: negotiating the social practices of hospitals in England, 2018.

⁵⁴ Burton et al. Access to Medicare-funded Annual Comprehensive Health Assessment for Rural people, 2013.

⁵⁵ Nicholson L. & Cooper SA. Access to healthcare services by people with intellectual disabilities: A Rural-Urban comparison, 2011.

⁵⁶ Hussain R, & Tait K. Parental Perceptions of Information Needs and Service provision for Children with Developmental Disabilities in Rural Australia, 2015.

⁵⁷ Gibson J. & O’Connor R., Access to health care for disabled people, a systematic review, 2010.; Drainoni et al. Cross-disability experiences of barriers of health-care access: consumer perspectives, 2006.

⁵⁸ Scheer et al. Access barriers for persons with disabilities: the consumer’s perspective, 2003.

⁵⁹ Sakellariou et al. Barriers to accessing cancer services for adults with physical disabilities in England and Wales: an interview based study, 2019.

experienced lack of adequate preparation both from healthcare professionals and healthcare facilities, as to response to their needs. Overall, participants of this study reported that the healthcare systems and staff to be inadequately prepared to address their needs, that their needs were often unseen, and that healthcare professionals are often not properly equipped to manage the effects of disability on their overall care and their cancer-related care. In the Report on the Independent Inquiry of the Department of Health UK⁶⁰, into access to healthcare for people with learning disabilities, men and women received poorer quality of healthcare they are entitled to, with a general lack of awareness or indifference to the special needs of patients with learning disabilities, and carers which are often there to advocate on the patient's behalf, are left ignored. General practitioners, on the other hand, also identified communication as the main problem when consulting with patients with learning disabilities, and preferred it these patients were accompanied by a carer who was able to help with regards to any miscommunication that happens.⁶¹

Four French reports⁶² recommended in their findings, that awareness on the health issues for persons with intellectual disabilities should be raised to suppress barriers to healthcare. In addition, a Netherlands study found that 48% of the doctors questioned felt that they had insufficient time to communicate effectively with patients with intellectual disabilities.⁶³

Communication barriers

It has been widely reported that communication barriers between health services professionals and people with disabilities are a big challenge.

Barriers are not only found in the direct communication between staff and people with disabilities, but also in the indirect communication, such as brochures, campaigns and other types of information dissemination. For example, people with learning disabilities may have to endure communication difficulties, in a way that they cannot give reliable reports of their symptoms and/or deal with examinations, investigations, and treatments, due to anxiety-

⁶⁰ Department of Health UK. Healthcare for all: Report on the Independent Inquiry into access to healthcare for people with learning disabilities, 2008.

⁶¹ Ibid.

⁶² Pour une santé accessible aux personnes handicapées mentales. Paris: Union nationale des associations e parents, de personnes handicapée mentales et de leurs amis; 2013.; Haute Autorité de Santé – Audition publique “Accès aux soins des personnes en situation de handicap”, 2008.; ANAES. Hôpital Handicap: Pour une amelioration continue de la qualité dans l'accueil et les soins pour les personnes handicapées à l'hôpital, 2002.; Observatoire national sur la formation, la recherche et l'innovation sur le handicap. Rapport triennal de l'Observatoire national sur la formation, la recherche et l'innovation sur le handicap, 2011.

⁶³ ANED, Country reports on accessibility of healthcare, 2014.

provoking changes in their daily routines.⁶⁴ This may also lead to diagnostic overshadowing, where people's symptoms are wrongly attributed to their disability.⁶⁵

In a study⁶⁶ on people with learning disabilities, carers and care workers regarding the awareness of health risks and implications for primary care, the findings concluded that people with learning disabilities are likely to have complex support needs, with major communication challenges for those with severe learning difficulties. In this sense, care workers have been found to be as key supporters, the ones with in-depth knowledge of their clients, as to best inform and facilitate care, needs and potential treatments. The study also found that it is essential to engage people with learning disabilities and their supporters in health improvement dialogues, especially when discussing primary care.⁶⁷

Several of the generic evaluations of healthcare quality mentioned in the country reports⁶⁸ indicated that communication was an issue of particular concern. In the evaluation carried out by the Ministry of Health in the Czech Republic in 2010,⁶⁹ for instance, patients reported that 'information and communication' was the most problematic aspect of healthcare quality in rehabilitation institutions (for people with Physical disabilities) and psychiatric services.

Poor communications with medical staff were highlighted as an area of concern in an Irish survey of patients in acute hospitals.⁷⁰ Also of interest is a Macedonian study on healthcare communications which has drawn attention to on-going barriers to healthcare communications associated with cultural and religious diversity, but disability-related barriers were not considered.⁷¹

In Romania, based on a sample of 41 county hospitals, findings were that only 20% of hospitals had access to sign language interpretation (through cooperation with NGOs) and none had accessible telephones (adapted for use with people with hearing impairments) or access to pictograms or easy read to support communication with people with intellectual disabilities, and less than 17% of hospitals have websites adapted to the needs of people with disabilities.⁷²

⁶⁴ BBC. Treatment decisions for people who can't give informed consent, 2007.

⁶⁵ Ibid.

⁶⁶ Young et al. People with learning disabilities, carers and care workers' awareness of health risks and implications for primary care, 2007.

⁶⁷ Ibid.

⁶⁸ ANED, Country reports on accessibility of healthcare, 2014.

⁶⁹ Czech, Ministry of Health study, 2010.

⁷⁰ <https://www.hse.ie/eng/services/publications/hospitals/national-patient-experience-survey-2018.pdf>

⁷¹ Pollozhani A et al. Some Aspects of Culturally Competent Communication in Healthcare in the Republic of Macedonia, 2013.

⁷² ANED, Country reports on accessibility of healthcare, 2014.

Despite the low profile of accessibility of healthcare communications in generic healthcare, disability strategy and complaint data bases, the question has been tackled in a range of more focused studies on this specific topic. These identify various barriers to the accessibility of healthcare communications in practice as well as examples of how, in some countries or healthcare organisations, accessibility appears to have been achieved. Taken as a whole, however, they indicate that many people with disabilities remain excluded from or disadvantaged in accessing healthcare services because of inaccessible communications. One Slovenian researcher reported that, for the purpose of the ANED study on country reports on accessibility to healthcare, one expert described communication with people with disabilities as “the weakest point of the medical staff”.⁷³

Inaccessible buildings and equipment

Inaccessible health facilities and equipment have been reported in literature to be one of the biggest barriers in accessing healthcare services. In the study mentioned on the barriers to accessing cancer services faced by adults with pre-existing disabilities in the UK, participants also reported inaccessibility to healthcare facilities,⁷⁴ which also reflects on the previous studies that show physical inaccessibility to be a major barrier while trying to access services. Iezzoni⁷⁵ has shown in a study on access to diagnosis and treatment for breast cancer for women with mobility impairments that they are facing significant barriers related to access, including problems getting into health practitioners’ offices and using examination equipment, concluding that the existence of the accessible equipment does not guarantee usability.⁷⁶

Long waiting lists

Healthcare systems where healthcare is free, as a general principle, often place restrictions as to restrain costs.⁷⁷ These restrictions may imply waiting times, used as a tool for priority setting, which may, however, become a major problem if the health system is not able to provide healthcare within and acceptable time to patients, and with that taking into account

⁷³ Jelka Bratec, (an expert with long term experience as a leader of the sheltered employment Organisation Sonček in Ljubljana), 2014.

⁷⁴ Pour une santé accessible aux personnes handicapées mentales. Paris: Union nationale des associations e parents, de personnes handicapée mentales et de leurs amis; 2013.; Haute Autorité de Santé – Audition publique “Accès aux soins des personnes en situation de handicap”, 2008.; ANAES. Hôpital Handicap: Pour une amélioration continue de la qualité dans l’accueil et les soins pour les personnes handicapées à l’hôpital, 2002.; Observatoire national sur la formation, la recherche et l’innovation sur le handicap. Rapport triennal de l’Observatoire national sur la formation, la recherche et l’innovation sur le handicap, 2011.

⁷⁵ Iezzoni et al. Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments, 2010.

⁷⁶ Ibid.

⁷⁷ Siciliani et al. Waiting times policies in the health sector: What works? 2013.

their healthcare needs and conditions. The Report on the inequalities in access to healthcare found that in some countries waiting lists are an issue for the entire health systems, while in others they exist only for a certain types of care. Waiting lists along with costs and travelling distance, present major barriers to achieving equality in accessing healthcare services.

General findings

In a report on the outcomes of a health screening programme after 1 year for people with intellectual disabilities⁷⁸, findings have shown that men and women with learning disabilities are more inclined to have poorer health than people without disabilities; with the access to primary healthcare through general practice surgeries, access to secondary healthcare through general hospitals and community mental health service. In addition, they are also entitled to support from specialist community learning disability services. However, the report found that this tripartite division of healthcare can lead to confusion of which services to choose, due to uncertain boundaries of these services and under which circumstances people with learning disabilities should be accessing primary or other two types of care. In these blurred environments, patients are known to ‘fall’ between services, where no particular professional has overall responsibility for the patient’s care and needs.

The French research study⁷⁹ showed the results comparison of average dental care in lower average use of dental care by people with disabilities, being about 50%, which is 6 percentage points lower than the general population. In terms of demographic variables, it was noted that the probability of using dental care varies according to the age and gender of individuals. Indeed, the probability of dental care is 10 points higher for women, an effect found also in other studies.⁸⁰ However, it has also been reported that the dental care is increasing with age, as well as that socio-economic variables such as complementary health insurance, diploma and income also changes the likelihood of using dental care.⁸¹ Geographical factors also play an important role, as it was concluded that people residing in multi-polarized municipalities, in the municipalities of an employment centre in rural areas or residing in Lyon, Paris or Marseille have a higher probability of using dental care services. Additionally, for dental care

⁷⁸ Cooper et al. Improving the health of people with intellectual disabilities: Outcomes of a health screening programme after 1 year, 2006.

⁷⁹ Lengagne P et al. L'accès aux soins courants et préventifs des personnes en situation de handicap en France, 2015.

⁸⁰ Lupi-Pegurier L., Clerc-Urmes I., Abu-Zaineh M., Paraponaris A., Ventelou B. Density of Dental Care for the Elderly: A Multilevel Analysis with a View on SocioEconomic Inequality, 2011.

⁸¹ Ibid.

is a clear gap between the lowest and the highest income countries, where countries with low coverage for dental care perform substantially worse in access to dental care, where the low income groups are even more affected.⁸²

Access to ophthalmological care for people with disabilities must be the subject of particular attention, especially since some disabilities are likely to generate visual difficulties that increase the need.⁸³ Even though the need for care may be for people with disabilities, a barrier to access may lie in the difficulty in expressing these care needs. In the study conducted, the probability of using ophthalmological care is 0.19, or about one in five people. For people with disabilities, the average use of eye care is higher than for other people.⁸⁴

For women with disabilities, barriers to access to gynecological care as previously reported in were numerous: difficulties in accessing structures, difficulties in accessing some exams due to inappropriate equipment, with not enough progress, barriers are still prevailing. One of the recommendations of the Jacob report⁸⁵ is to "systematize preventive follow-up in gynecology and obstetrics for women with disabilities and actions to prevent sexually transmitted infections", which suggests that little progress has been made so far.

Various research has been conducted over the years with regards to the access to healthcare for people with disabilities, with many of them reviewing eligible papers on quality of care and practical access to healthcare. One such study⁸⁶ reviewed sixteen studies between 2009 and 2013 that addressed the experiences of people with intellectual disabilities in general acute care hospitals. The overall themes that emerged from the studies indicated that, despite 20 years of research and government initiatives, the target group continues to experience fear in relation to hospital visits, still relying on family carers to provide the necessary care as well as to ensure they receive adequate health assessment and treatments they need. Also, it is still apparent that negative attitudes from hospital staff and nurse is still not sufficiently addressed⁸⁷, with one study pointing out that hospital staff themselves recognized the need for further training as per lack of knowledge and skills when dealing with people with intellectual

⁸² EU Commission - Baeten R Et al. Inequalities in access to healthcare, A study on national policies, 2018.

⁸³ Evenhuis, H.M., Theunissen, M., Denkers, I., Verschuure, H. Kemme, H. Prevalence of Visual and Hearing Impairment in a Dutch Institutionalized Population with Intellectual Disability, 2001.; Krinsky-McHale S.J., Jenkins E.C., Zigman W.B., Silverman W. Ophthalmic Disorders in Adults with Down Syndrome. 2012.

⁸⁴ Lengagne P et al. L'accès aux soins courants et préventifs des personnes en situation de handicap en France, 2015.

⁸⁵ Jacob P. Un droit citoyen pour la personne handicapée, un parcours de soins et de santé sans rupture d'accompagnement. Ministère délégué chargé des personnes handicapées et de la lutte contre l'exclusion, 2013.

⁸⁶ Iacono T et al. A systematic review of hospital experiences of people with intellectual disability, 2014.

⁸⁷ Ibid.

disabilities.⁸⁸ Additionally, a need for further research was recognized, particularly with regards to the specific points of encounter along the patient journey, as well as with the patients' experiences when it comes to other vulnerable groups.

A systematic review of access to general healthcare services for people with disabilities in low and middle income countries⁸⁹ found that supporting evidence that people with disabilities are being left behind on the universal health coverage path. With 50 studies included in this review, there was a general conclusion that there is no uniform method of measuring disability and healthcare access which made it more difficult in generating conclusions, and also made ground for any bias in researching for data on access to healthcare for this group of people. For this reason, it is highly important to develop common metrics for measuring disability and healthcare access, as it will improve the chance for high quality data, and with that proper and achievable results in ensuring that the rights of people with disabilities with regards to their healthcare access are met.⁹⁰

Lack of appropriate referral remains a core problem in the delivery of care for people with intellectual disabilities. Tremblay and Morin⁹¹ used an expert committee to review participants' files in order to determine the client-related variables that were associated with the level of service provided. They found that of the 30 participants, ten were not receiving the appropriate level of care. Lower levels of care were most strongly associated with the perceived challenging behaviors of clients. Their conclusion was that the primacy of clinical judgement, rather than the specific participant characteristics, affect whether people with intellectual disabilities is referred to services which best meet their needs.

The idea of mapping patient journeys for people with intellectual difficulties has been discussed in the report - Capacity building and intellectual disability health services,⁹² where findings showed the absence of evidence driven responses, concluding that the mapping of patient journeys could provide the start of a process for identifying vulnerabilities across the entire health systems, from the primary to the tertiary, as well as showing patients' experiences. Their findings also suggested that these maps could also demonstrate types of

⁸⁸ Castle A, et al. Experiences of the Implementation if a learning disability nursing liaison service within an acute hospital setting: A services evaluation, 2013.

⁸⁹ Bright T, & Kuper H. A systematic review of access to general healthcare services for people with disabilities in low and middle income countries, 2018.

⁹⁰ Ibid.

⁹¹ Tremblay A, & Morin D. Assessment of an Expert Committee as a Referral Process within Health and Social Services, 2015.

⁹² Travaglia J Et al. Capacity building and intellectual disability health services, 2017.

services which need to be integrated, needs of capacity building, as well as location of these needs.

The study on access to healthcare for people with disabilities⁹³ found that five patients (third of the sample) had not been referred (or experienced delays in referral) to specialist services for people with intellectual disability, and that carers had little knowledge of such services. The study also found that there were some examples of services making reasonable adjustments for people with intellectual disabilities in their access to healthcare, such as providing a longer appointment slot, and inviting patients to see the ward before surgery, the conclusion was that more progress needs to be made by health services to ensure that reasonable adjustments are made in order to reduce both indirect and direct discrimination of people with intellectual disability. Adjustments that could be incorporated by mainstream services include easy read (accessible) clinic letters, and information on medication and procedures; the use of a communication or health passport to communicate health needs and treatment changes; allocation of longer appointment slots or offering the first appointment and making appointment booking systems easier to use.

Good practices in removing barriers to accessing healthcare for people with disabilities

The success story of an interventional project – ‘The Disability Project’,⁹⁴ which was conducted between 2012 and 2017 in Geneva Hospital, has gained recognition by entering in the 2020 strategic planning of the largest hospital in Switzerland. Switzerland does not have a national policy regarding health needs for patients with intellectual and developmental disabilities and health care professionals are not trained to identify and meet the specific needs of this population and little is taught about this topic during undergraduate studies. The project was designed to identify the specific needs of people with intellectual and developmental disabilities, the barriers of providing equity of care and to prioritize reasonable adjustments. Based on the findings of these priorities, interventions were developed.

The Disability Project outcomes have proved to be major achievements in terms of bettering the position of people with disabilities: through the creation of the “Disability Webpage” and

⁹³ Ali et al. Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers, 2013.

⁹⁴ Raemy, SL & Paignin A. Providing equity of care for patients with intellectual and developmental disabilities in Western Switzerland: a descriptive intervention in a University Hospital, 2019.

the video of the project, the project changed made this group visible; the specific admission sheet was created and standardized as it relieves the parents and carers from repeating the relevant information, as well as it helps the hospital staff to quickly get the necessary information, which in itself proved to be a great success. The most important achievement was the creation of two positions – the ID Nurse Case manager and the ID Physician, which have become essential for project implementation, and proved to play a critical role in terms of having the right skills, training hospital staff about people with intellectual disabilities; and the second main achievements were the short waiting time, the central phone number and the disability admission sheet.⁹⁵

The project also had impact on the human capacity, developing a specific training program for student nurses at the University of Applied Sciences and the Arts of Western Switzerland, as it has become evident that it is highly important to train the future hospital staff on specific needs of the people with intellectual disabilities. Consequently, due to high success of the Project, a specific disability out-patients clinic was created, and directed by the ID physician.⁹⁶ It should be stressed out that the Disability Project has achieved many reasonable adjustments in an acute care setting as to provide good care and satisfaction for people with disabilities and their families.

The Report on Healthcare for all from the Department of Health UK⁹⁷, found evidence on good practices of staff dealing with people with disabilities, such as: training initiatives where staff could learn more about people with disabilities, the introduction of ‘passports’ informing the staff of patients’ disabilities and special needs, and the introduction of liaison nurses to guide staff on acute hospital wards in how to make ‘reasonable adjustments’ for people with disabilities. However, these practices, where they were found were stemming from individuals, and not centrally coordinated efforts to improve the access to healthcare for people with disabilities.⁹⁸

In Ireland, The National Disability Authority has produced an Accessibility Toolkit to make public services more accessible, which includes healthcare services.⁹⁹ The toolkit addresses

⁹⁵ Ibid.

⁹⁶ Ibid.

⁹⁷ Department of Health UK. Healthcare for all: Report on the Independent Inquiry into access to healthcare for people with learning disabilities, 2008.

⁹⁸ Ibid.

⁹⁹ National Disability Authority. Accessibility Toolkit, <http://nda.ie/Resources/Accessibility-toolkit/>, seen December 2019.

how to accommodate person with different disabilities. For customers with hearing difficulties the NDA suggests, for example:

- Provide queuing systems that do not rely on customers' ability to hear;
- To help people who lip-read, make sure there is no shadow on your face while you speak;
- Provide induction loop systems—and test them regularly;
- Make captions available for videos, and make transcriptions available for audio information;
- Providing written versions of any audio notices and communications;
- Allowing customers to use text messages and e-mail to make appointments;
- Providing ISL (Irish Sign Language) interpretation to customers who request it;
- Talking directly to the Deaf person, and not the interpreter;
- Not asking the interpreter's opinion;
- Making sure that the interpreter sits next to you and that the Deaf person can see both of you clearly.¹⁰⁰

The NDA toolkit also discusses how to best accommodate persons with other disabilities. They suggest for example that for clients that are anxious or depressed that services allow extra time for these and that they are allowed to bring an advocate, friend or family member to appointments and to encourage breaks.¹⁰¹

There are also examples of good practice in which sign language interpretation is made readily available. In Austria, the hospitals of the Barmherzigen Brüder in Vienna, Salzburg and Linz offer sign language in the context of medical staff-patient communication and operate outpatient clinics for deaf persons (Gehörlosenambulanzen).¹⁰²

There are many systems in various countries implementing digital solutions for a better access to healthcare services, such as online interpretations for deaf people, as one Finnish study suggests that many deaf people prefer remote communication to having a sign language interpreter present in person – especially where the nature of the consultation is particularly sensitive or potentially embarrassing.¹⁰³

¹⁰⁰ National Disability Authority, Accessibility Toolkit <http://nda.ie/Resources/Accessibility-toolkit/Make-your-services-more-accessible/> seen December 2019.

¹⁰¹ Ibid.

¹⁰² ANED, Country reports on accessibility of healthcare, 2014.

¹⁰³ Topo, P et al. Kuulo- ja puhevammaisten tulkkipalvelut. Vammaispalvelulain toteutuminen, 2002.

Such systems operate in a number of hospitals in Belgium¹⁰⁴, Finland¹⁰⁵, Portugal¹⁰⁶, and in a range of health facilities (including hospitals) in Ireland. In the Czech Republic, the organisation ‘Agentura neslyšících APPN’ (a counselling agency for the deaf and hard of hearing people) established in 2013 the online interpretation service around the clock. The service is based on sign language interpretation "at a distance". An interpreter is located at a place other than with the client. The sign language is transmitted via webcam while transmitting speech through a normal phone. This service allows interpreting between a deaf person and a doctor. In addition, APPN has been recently distributing to the Czech hospitals tablets which facilitate medical staff to communicate with deaf persons. In Luxembourg the national emergency unit is working on a system to send emergency information on smartphones or on other electronic equipment for persons with hearing disabilities.¹⁰⁷

Strengthened health and human services workforce capacity

A systematic review¹⁰⁸ in order to synthesize qualitative research studies on nurses’ experience of caring for patients with intellectual developmental disorders (IDD) was undertaken as to develop an understanding on registered nurses’ experiences. The review included 18 published studies from 8 different countries involving 190 registered nurses, with the overall conclusion of the lack of awareness and knowledge to be a breeding grounds for exclusion that still surrounds this group of patients. In more detail, the findings suggest that negative stigmatization, attitudes and exclusion are still very present when dealing with this group of patients, as well as lack of real awareness for services that need to be designed to meet the healthcare needs of these patients. Challenges that were encountered mostly are related to complex health conditions, communication difficulties and challenging behaviors. Findings also indicated that creating a long-term relationship with the in the IDD patient which would constitute of more than a verbal communication, could be an option for the registered nurses to work with these patients in a person-centered way.

¹⁰⁴ Association Socialiste de la Personne Handicapée: Les personnes sourdes face aux inégalités d’accès aux soins de santé de qualité, 2013, p. 7.

¹⁰⁵ A call service for older people, people with disabilities and people with mental health problems living in their own homes was piloted in the ERNET project of the hospital district of South-Savonia, Finland. ANED Country Reports, 2014.

¹⁰⁶ Ibid.

¹⁰⁷ Ibid.

¹⁰⁸ Appelgren M, et al. Nurses’ experience of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach, 2018.

Also, the review showed that, with only few exceptions, little attention has been given to these group of patients in nursing research, as well as a reoccurring theme of the lack of awareness and adequate skills by the registered nurses which is probably one of the main reasons for the perpetuate exclusion of this group of patients.¹⁰⁹

Most of the studies, (along with systematic reviews) in the existing literature included calls for competency-based¹¹⁰ healthcare or staff training and/or development¹¹¹, including from students and general practitioners themselves.¹¹² The actual training and education of medical professionals and students have had mixed result, where diversity of curricula , context, characteristics of participants and other factors, makes their finding impossible to generalize.

Additionally, part of improving quality of services requires a better understanding of clinician attitudes and capabilities, which is not simply a matter of further training. There have been two issues which were identified when working with people with intellectual difficulties – that of clinician ‘fear’ of people with disabilities’ lack of certainty if responses, and the issues of diagnostic overshadowing. This refers to the recognition of complexity of conditions this group faces, and the additional time and resources needed in order to respond adequately.¹¹³

Throughout the literature there were examples of poor treatment, diagnostic overshadowing and negative staff attitudes towards individuals with disability, suggesting that more needs to be done in ensuring that health professionals receive adequate training. One positive example of training is the online module in intellectual disability produced by the General Medical Council in the UK, which is aimed at providing doctors with the knowledge and skills required to effectively communicate and treat people with intellectual disabilities.¹¹⁴ This resource is freely available and could be used more widely as a teaching aid for health professionals across a range of disciplines.

¹⁰⁹ Ibid.

¹¹⁰ Johnson K Et al. Competency based advanced training in Intellectual Disability Psychiatry: A New Prototype, 2013.

¹¹¹ Walsh N Et al. Training and developing staff in General Hospitals: Intellectual Disability Liaison Nurses and the Raid Model, 2014. Marsham M. Raising Awareness of Learning Disability Needs in Acute Sector Care: A Reflective Account of a Workshop from the Guest Facilitator Perspective, 2009.

¹¹² Vermelfoort K Et al. Attitudes towards Adults with Intellectual Disability: A survey of Ontario Occupational and Physical Therapy Students, 2014.

¹¹³ Travaglia J. Et al. Capacity building and intellectual disability health services, 2017.

¹¹⁴ General Medical council website. Available: www.gmc-uk.org/learningdisabilities, seen December 2019.

Bridging the disability divide through digital technologies

There is an often-cited quote by Mary Pat Radabaugh, formerly with the IBM National Support Center for Persons with disabilities, that sums up the importance of technology in the empowerment of people with disabilities: “For most people, technology makes things easier. For people with disabilities, technology makes things possible.”

Information and Communication Technology (ICT) is making possible for people with disabilities to engage on a more equal level in the field of education, employment and community inclusion. ICT enables the use of multiple ways of communication – voice, text, and gestures – to access information and engage with the community, breaking down barriers of communication people with disabilities are facing in their everyday life. ICT is clearly defined as an enabler in the Convention on the Rights of persons with Disabilities (CRPD).

This is highly visible as everyday ICT, such as mobile devices and computers offer functionalities that facilitate communication and information for people with disabilities.¹¹⁵ Many features, such as text-to-speech and voice recognition, ability to change contrast and color schemes, touch and gesture input are becoming mainstream and relevant. Digital technologies offer a person with disabilities to receive information and content in the format they prefer, such as a person with visual impairments can use speech-to-text functionality or software to read a website, and a person with hearing impairments can use SMS to communicate. When multiple options of communication exist, people with disabilities can choose the one most suited for their functionality. This in all shows the opportunity to break barriers of communication and interaction for people with disabilities, and their equal inclusion in a society. With regards to people with disabilities, ICT has been proven to be most valuable in the case of disaster management, when access to instant and relevant information can save lives and reduce injuries, as well as to prepare people with disabilities, their carers and response personnel to adequately react and in a timely manner.¹¹⁶ However, in order to consider ICT as a factor in overcoming disparities that people with disabilities are facing, ICT need to be designed in a way they are accessible and inclusive, otherwise they can widen the already existing inequalities.¹¹⁷

¹¹⁵ Raja DS, World Bank Group, Bridging the Disability through Digital Technologies, 2016.

¹¹⁶ Ibid.

¹¹⁷ Ibid.

However, there are still challenges in the widespread use of accessible ICTs, with a visible disconnect between what ICT can do for people with disabilities and real life examples. The latest G3ict CRPD 2016 ICT Accessibility Report, which assesses progress towards ICT component implementation, found that a majority of the 106 participation countries did not have accessible government websites (53%), accessible public electronic kiosks (85%), or does not have any government fund allocated to programs in support of Digital Accessibility (80%).¹¹⁸

Discussion

Health inequalities can be reduced by making existing health care systems more inclusive at all levels and making health programmes more accessible to people with disabilities. As there are multiple factors that limit and influence access to healthcare for people with disabilities, different actions are needed in all components of healthcare systems, including improving governance and increasing levels of awareness, knowledge and data on issues related to health disparities people with disabilities are facing, so that relevant actors may better consider disability and increase access to services. National health care policies need to acknowledge formally that these inequalities exist, as well as put more light onto the community-based rehabilitation, as an important means of ensuring and improving access to health related services, particularly in rural and remote areas. For healthcare services to be truly inclusive, they need to be relevant and patient-centered, considering and not ignoring or minimizing the disability and the effects on treatment.

People with disabilities need to be engaged in decision-making process when it comes to access to health, as it will also help in bringing down barriers and offer an improvement with regards to these services. This should be done in a way that is inclusive to all level and forms of disability, taking into consideration that the modes of communication meet the requirements of persons with disabilities.

There are multiple access barriers to appropriate health care for people with disabilities. Too often people with disabilities find that medical providers do not demonstrate respectful attitudes toward them and make inappropriate assumptions about their needs. Lack of sufficient time for appointments, physical inaccessibility, cost of care and transportation present additional barriers. Patients may defer necessary appointments because of past

¹¹⁸ <https://g3ict.org/publication/2016-crpdpd-ict-accessibility-progress-report>

experiences where they felt disrespected by providers who did not seem to care about their input, and whom they feared may not have put enough value on their lives. The special importance is given on the effective communication between patients and their doctors, as it is dependent on the practice of patient-centered care. The more comfortable the patient are with their healthcare service providers, the more they are willing to attend the follow-up appointments and practice self-care. Improvements of the communication prove to be an important way to create improved overall health outcomes and patient satisfaction, thus decreasing the inequalities that exist between disabled and non-disabled persons in terms of access the healthcare. Additionally, health care providers need to be provided with additional training where required, so they have the skills to provide physical access to care for people with disabilities.

The key to providing safe healthcare for people with disabilities is the implementation of reasonable adjustments, which requires that the patient is identified in the healthcare system as having disabilities, as well as making reasonable adjustments for the patient's healthcare service delivery. It is highly important that healthcare professionals and healthcare workers work toward inclusive healthcare environments, acknowledging the existence of disability and enabling better utilization of services by all patients. Necessary steps need to be taken as to develop an enabling environment which will fuel better communication between different specialists involved in a patient's care, train and work on developing skills for medical professionals about strategies for monitoring symptoms for people unable to feel or express them, as well as work toward making healthcare services more physically accessible.

Conclusion

Identification of evidence on access to healthcare services for people with disabilities is critical as part of an ongoing process of appropriate and effective healthcare services development. This review highlighted significant barriers, as well as initiatives aimed at improving access to healthcare services for people with disabilities, as it is important for the effort to overcome gaps and barriers to focus on identifying and implementing issues and effective innovations as solutions. Providing good access to health for people with disabilities will ensure that their rights are met and help, which will also back the effort in reaching universal health coverage, as by reaching the whole population will enable that people experience better health, productivity and with it, less poverty. However, even though some improvements to services



as a result of health policies and recommendations have been achieved, more progress is required to ensure that health services make reasonable adjustments to reduce both direct and indirect discrimination of people with disabilities.

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