



Jimmy will come to collect the test results, or how (not) to talk about disability



JOANNA MATUSZEWSKA
medical journalist, rehabilitation
manager and specialist in integrated
rehabilitation at the Breast
Disease Unit, University Clinical
Centre, lecturer at the Department
of Research on the Quality of Life

None of us wants to discriminate against people with disabilities (PwD). What, then, are the reasons for gaffes, incorrect behavior, inappropriate rhetoric? There can be many reasons, but often they are the lack of knowledge and experience. What does an average able-bodied person know about the functioning of people with disabilities? Often they don't even know any person with a disability personally. Usually our knowledge is superficial, somewhat TV-like. We know what the media show, and in them we either have heroes and conquerors, or people incapable of independence. Some boast of another peak that they reached despite their physical or mental condition or intellectual limitations, others are people who are struggling, asking for help or complaining about the "system". This division is incomplete and inconsistent with reality. Among PwD there are also those who work, have families, children and problems similar to able-bodied people. Their dysfunctions are not always visible. However, there is something that they experience for most of their lives – they struggle with stereotypes, and often with discrimination due to their disability.

FIRST THE PERSON, THEN THE DYSFUNCTION

Even people with medical education and psychologists lack knowledge about disability. First of all, it is worth knowing that we are talking about a person with a disability, not a disabled person. The difference seems small, but empowering a person and only then noticing their dysfunction is of great importance for the environment.

Less and less often, although we can still hear them, expressions such as "invalidity" or "lameness" are used. "Dysfunction" or "fitness level" or "disability" sound much better for some reason. No one will be offended if we say that someone has special needs. This quite broad term includes the elderly, pregnant women or people with problems with moving, seeing, hearing, functioning in the environment.

JIMMY WILL COME TO COLLECT THE TEST RESULT

Respectful treatment and acknowledging the needs of people with disabilities is what is most deficient. People with disabilities point out that able-bodied people do not always know how to behave. For example, during a conversation, they do not address them directly, but communicate through the people who accompany them. A blind 45-year-old man told me that whenever he was a patient and his wife was with him, she was the one who talked about his health. *In turn, when someone addresses him, he begins to speak louder, slower and clearer. I feel humiliated then. I am blind, and they treat me as if I am below the intellectual standard* – says Mr. Sławomir.

Another example is the condescending treatment of adult PwD. This may take the form of shortening the distance, diminutive words and contact with "Jimmy", and not Mr. James or James, or lenient treatment, different than in relation to able-bodied people.

I SEE NOTHING, I HEAR NOTHING

People with disabilities, especially wheelchair users, point to communication problems related to making appointments at private offices. Many of them, unlike public institutions, still operate in buildings without elevators and ramps. *Very often there is no information about this on the website. It is also not provided at the stage of arranging a visit, even though I inform you that I am in a wheelchair. It's as if I was expected to come with four people to carry me up the stairs, says a 30-year-old woman. She adds that it is also a challenge to register at a clinic or fill a prescription at a pharmacy. Tops, windows are too high for a person sitting in a wheelchair. I can't see and I can't hear the person on the other side well enough. I can't enter the PIN at the payment card terminal. A reasonable pharmacy employee or a medical registrar will come out from behind the counter, but not everyone wants and knows how to help me, adds the woman.*

It is also a sign of equal treatment to conduct a conversation with a person in a wheelchair by e.g. medical personnel (doctor, nurse, therapist) in a sitting position to adjust to the line of sight of the interlocutor.

People who are deaf or with hearing deficits also pay attention to the problems. Most health facilities do not



have inductive loops to facilitate communication for people using hearing aids. Clinics and emergency departments are not equipped with communication cards with a deaf person, thanks to which you can efficiently collect an interview, especially in emergencies. Many people do not know that it is possible to communicate with a deaf patient via an online sign language interpreter. In some centers there is no registration via SMS or the Internet, which excludes deaf people.

DIGNITY, OR “WHY DO YOU NEED A CHILD”

People with disabilities point out that they often feel stubbornly observed by random people in public space, they are also often subjected to inappropriate remarks, questions about sexuality, personal hygiene or procreation plans. Gaffes and remarks are sometimes cruel. *I can't imagine an able-bodied woman hearing “Why do you have a child? How are you going to raise them in this wheelchair?” These outrageous words were directed at my wife – Mr. Marek complains.*

Another problem is disregard. *No one listens to us. As a tetraplegic, I have low blood pressure. This condition is indicated for problems with neurogenic bladder dysfunction. Meanwhile, whenever I appear, for example, in the emergency department, the staff wants to raise my blood pressure pharmacologically. They don't listen to what I say about my health – says Magdalena.*

The way of caring for patients who cannot move independently and take care of their hygiene is also painful and difficult to accept. *In hospitals and sanatoriums it is extremely embarrassing when a man performs hygienic activities on me. I'm lying naked, catheterized on the bed and being washed with a sponge. It's a really traumatic experience, I feel stripped of my dignity – says one of the women.*

I CAN'T SPEAK, BUT I SEE WHAT YOU'RE DOING

It is worth remembering that people with disabilities can communicate in a non-verbal way. Just because someone cannot speak does not mean you can't communicate with them. There is an Augmentative and Alternative Communication (AAC) system, thanks to which non-speaking people with intellectual disabilities can express their needs, establish relationships and build a sense of independence. They use a wide

range of techniques and tools with ready-made visualizations of gestures, packages of symbols and pictures.

My friend's adult disabled daughter has cerebral palsy and cannot speak. Thanks to AAC, she communicates with her loved ones, chooses clothes in the store, decides what and when she wants to eat or what program to watch on TV. People who do not communicate verbally are very often aware of the behavior of other people, they pay attention to facial expressions, eye contact, body language. Ignoring their presence and disregarding them is also a form of discrimination.

VISIT WITHOUT THE QUEUE BUT... IN HALF A YEAR

Since 2018, people with a significant degree of disability have the right to priority-access to medical care (out of the queue) and without limits. They do not need a referral to a specialist doctor. This generates many misunderstandings, because this right is difficult to implement. First, too many people want to take advantage of it. Secondly, healthcare workers are not always aware of these privileges. *So what if there is a right to visit on the same day or as soon as possible. This is unrealistic, because usually you have to wait several months. Fortunately, you have to “discuss” about these privileges less and less often – says Mr. Adam, a person with a locomotor disability.*

INDEPENDENT PEOPLE LIKE YOU

Disability does not always mean the need for assistance. It is worth asking if anything can be done before we start helping or replacing PwD. Adults want to be treated as independent people. They consider a wheelchair, cane or crutch to be an integral part of their personal space. Don't touch them, don't take them, don't put them away without permission. Think before you speak. Address the person with a disability directly, notice the person, not their dysfunction. If someone's speech is slow or slurred or the person has a hearing deficit, repeat what you want to say several times. You can also write it down on a piece of paper.

Don't make decisions for anyone else – being excluded from making decisions is discrimination. A person with a disability has the right to their opinion.

Just like you. ■

JOANNA MATUSZEWSKA