

## Life of a Disabled Person in the Mirror of Statistics

Feruzza Zagyrtdinova<sup>1</sup>, Nigorakhon Yakubova<sup>2</sup>

Corresponding author: Feruzza Zagyrtdinova, National University of Uzbekistan, Tashkent, Uzbekistan

<sup>2</sup>Nigorakhon Yakubova, Inha University, Incheon, Korea

*This article is based on publicly available statistical data on disability issues in the Russian Federation and Uzbekistan and personal experience of job search of one of the authors, Feruzza Zagyrtdinova. It suggests that disability is not a social, but economic burden of the society. Model of disability (be it medical or social), does not solve problems faced by disabled people, but the level of economic development of a country seems to play a larger role. Every country has its own strategy to maintain control over the growth in numbers of disabled people. Disabled people of 3<sup>rd</sup> group in Uzbekistan do not receive pension (disability allowance). In the Russian Federation the number of disabled people of 2<sup>nd</sup> group is decreasing and the number of disabled people of 3<sup>rd</sup> group is growing, whilst the overall number of disabled people is declining.*

**Keywords:** criteria of disability; extent of limitation of ability to work; job search; level of economic development; disabled people in Russian Federation, disabled people in Uzbekistan; pension.

In the Russian Federation and Uzbekistan, disability is defined in terms of ability to work (Kikkas, 2001). People with disability are categorized according to their capacity to work: group 1 includes those unable to work and who require constant care, group 2 - those with some ability to work and able to work in special conditions, whilst requiring no constant care, and group 3 - those who partially lost the ability to work, but may do part-time or casual work (Pension Law, 1993).

Job search for a disabled person is challenging in any country. In the case of one of the authors, Feruzza, the problem lies not only in disability, but citizenship as well. Before she moved to the Russian Federation in 2012 due to deterioration of her health and need for care, she lived in Uzbekistan. There, she taught philosophy and bioethics, simultaneously undertaking academic research (including disability studies). According to the Federal State Statistics Service of the Russian Federation, there are 13 million disabled people in the Russian Federation (FSSS, accessed 14th November, 2014).

Table 1. The number of disabled people in the Russian Federation from 2009 to 2014 (categorical break down)

	2009	2010	2011	2012	2013	2014
Total number of disabled people, thousands	13074	13134	13209	13189	13082	12946
Including: I group	1912	1920	1540	1515	1496	1451
II group	7248	7086	7306	7076	6833	6595
III group	3399	3609	3822	4038	4185	4320
Disabled children	515	519	541	560	568	580
Total number of disabled people per 1000 people	91,6	92,0	92,5	92,2	91,3	90,1

The number of disabled people in the Russian Federation approaches 10% of the population, recognized by the World Health Organization. As seen from the Table 1, the number of disabled people is 9% of population in the Russian Federation. In 2013 Feruza joined this number, when she received her permanent residency and went through a re-assessment of her disability. Since then she receives a state disability allowance and so-called natural 'social service package' (free high quality insulin in her case).

The dynamics of the number of disabled people for last 25 years in the Russian Federation is fluctuating. Between 1990 and 2004 the number of disabled people tripled, as the country rushed into 'democratization' in the disability arena. In late 2004 the government introduced new, more stringent criteria to determine disability. A significant number of people lost their disability status after the new criteria were introduced which led to a decrease in the number of disabled people.

Another trend can be seen: the decrease in the number of disabled people of Group 2 and increase in the number of disabled people of Group 3, with a decrease in the total number of disabled people. Feruza experienced this trend too. In Uzbekistan she had a status of a disabled person of Group 2, which is more severe in comparison to Group 3. In the Russian Federation she was given a status of a disabled person of Group 3 since childhood. One would think it is acceptable, as every country has its own criteria to determine disability. Nevertheless, it is difficult to deny an economic agenda to refuse the status of a disabled person of Group 2 since childhood. If Feruza received the status of a disabled person of Group 2 since childhood, she would receive almost double the amount in state benefits compared to what she is currently receiving (as a disabled person of Group 3 since childhood). Then she could have a choice: to work or not to work. Now she has no choice. When she tried to appeal,

a doctor of the medical-social examination board doubted the authenticity and credibility of Feruza's documents that she brought from Uzbekistan. Unfortunately, there is a preconception of rampant corruption in Central Asian republics in comparison to the Russian Federation, and thus migrants from these countries can be suspected a priori in unauthenticity of information in their documents.

In contrast to the Russian Federation, Uzbekistan, a former Soviet republic and a new country since 1991, the burden on the state budget was lowered by reducing the number of disabled people of Group 3. Amendments to the Law 'On state pension provision of the citizens' came into effect in 2011, giving pensions only to disabled people of the 1<sup>st</sup> and 2<sup>nd</sup> groups and cancelling pensions to disabled people of the 3<sup>rd</sup> group (Amendments to Pension Law, 2011). According to data of 'Off-budget pension fund' in 2010, the number of disabled people of the 3<sup>rd</sup> group receiving a state pension comprises of 19.9% of total disabled people in the country<sup>1</sup>. Initiators of these amendments justify changes in the pension determination through international experience, when mild forms of disability did not lead to disability allowance due to common diseases. Sometimes, people who worked and had mild forms of disability went through corrupted channels to receive their 3<sup>rd</sup> group disability. However, some disabled people, who failed to justify their degree of disability, felt a strong blow of fate.

Experts in the Russian Federation justified the new trend of reducing the number of disabled people of 2<sup>nd</sup> group through successful rehabilitation programs. For example, Feruza had surgery to replace her intra-ocular lens (due to cataract) free of charge and without bureaucratic

<sup>1</sup> available at: <http://maxala.org/anonimno/2997-uzbekistan-brosaet-svoih-invalidov.html>

delays. She had to purchase the artificial intra-ocular lens herself, which doctors claim to be of higher quality than the free lens provided by the state rehabilitation program. If the decrease in the number of disabled people can be achieved by an adequate rehabilitation system, then how can the figures of disabled people in developed countries be explained? For example, the number of disabled people in Finland is three times as many as in the Russian Federation (Bayazitov, 2010). These developed countries, Finland, in particular, do have successful rehabilitation programs; hence the number of disabled people is expected to be lower. Probably, a high percentage of disabled people in these countries can be a form of latent or potential unemployment. 'Mild' criteria of disability assessment arise from the fact that economy of developed countries can afford to support a large number of disabled people.

Another program mentioned by the government of the Russian Federation (collected legislation of the Russian Federation, 2012, No. 19, Art. 2334) is one to create working places specially equipped for disabled people at home and at companies of their employment by quota. The state promised bonuses for companies who employ disabled people. The success of this program can be judged and experienced by a disabled person himself/herself. Many disabled people search for jobs in a similar way: through friends, job vacancy advertisements, and/or job centres. It is difficult to search for jobs without being naturalised in the country. People without citizenship require a special permission from the immigration authorities for employment. Employers tend to avoid such procedures, except those whose businesses are based on low-qualified and, as a rule, low-paid labour of migrant workers, often in the field of construction, utility services or agriculture.

Therefore, Feruza started her active job search only after naturalisation. Hoping to find a part-time job as doctor of philosophy, she applied to a

local medical college and a university, where she got the reply "sorry, colleague, we have no vacant posts". She emailed her resume and a request for support from the Higher Education Department of the Ministry of Education of the Republic of Bashkortostan. Unfortunately, she never received a reply. She also searched for jobs in newspapers and through the Internet. It turned out that most job vacancies like telephonist operators and office workers are in fact multilevel marketing schemes, selling biologically active supplements, useless medical devices or dubious insurance services. Doubts regarding the quality of the products, and also the requirement of initial personal investments have deterred her from occupation of that kind.

Having a citizen's passport of the Russian Federation and the disability certificate, she applied to her city job centre. According to data of the Federal Service for Labour and Employment of the Russian Federation, the number of disabled people applied for a job at job centres is as follows in Table 2<sup>2</sup>.

*Table 2. The number of disabled people applied and found job between 2008 and 2013*

	2008	2009	2010	2011	2012	2013
Applied for help at job centres	256190	306478	268202	243407	211828	190631
Found job	87299	84651	87218	84980	76865	75642

It is unclear whether applying to job centres for job search means registering at job centre, but, in this case, apparently the credit should go to job centres. According to the table above, 40 % of disabled people who applied for jobs did eventually find a job. It reflects a reasonable success rate of the job centres. Although the

<sup>2</sup> FSLE, available at

<http://www.rostrud.ru/documents/25/xPages/page.2.html>

random sampling of disabled people showed that ‘77% of disabled people wanted to find a job (or change jobs) and 5% of disabled people participated in the poll wanted to start their own business, only 4% of disabled people apply for assistance at job centres to find a job,’ – said the deputy minister of labour and social protection of the Russian Federation, Tatyana Blinova, in May 2013. Only 32% of working age disabled people are working, according to Ministry of Labour and Social Protection<sup>3</sup>. However, Russian researchers have differing statistics: less than 10% of all disabled people work, the number of working age disabled people who are employed does not go beyond 15%, it is particularly low among disabled people of the 1<sup>st</sup> and 2<sup>nd</sup> groups (8%) (Kotov and Prisezkaya, 2009). Is it really possible to improve the employment rate of disabled people from 10% to 32% within four years?

Despite the ratio of disabled to non-disabled people in a particular country, the disparity between employed and unemployed disabled people and non-disabled people is obvious. According to the data of the Federal State Statistics Service of the Russian Federation, 3.7 million people (4.8%) were unemployed in August 2014, but actively searched for a job<sup>4</sup> and in accordance with International Labour Organization they are classified as unemployed. This number is much higher among disabled people. At the same time the maintenance of health requires additional expenses. For example, Feruza received 5 635,99 rubles in October 2014, including 1) pension 4 226,48 rubles; 2) monthly allowance 818,60 rubles; 3) monthly social protection allowance 590,91 rubles. The cost of

‘natural’ (barter) social services package is 881,63 rubles, which provides Feruza with free insulin. The decree of the Government of the Republic of Bashkortostan dated 4<sup>th</sup> August 2014 №360 sets the following subsistence minimum in the republic: ‘in average for month of 2<sup>nd</sup> quarter of 2014 per capita is 7243 rubles, for working population - 7707 rubles, for pensioners - 5904 rubles, for children - 7240 rubles’ (Resolution of the Government of the Republic of Bashkortostan dated August 4, 2014 No. 360). The decree does not mention specifically disabled people, who receive pension not due to age, but health condition. The city department of social protection (where Feruza lives) confirms that from 1<sup>st</sup> September 2014, the subsistence minimum for the working population, disabled people and pregnant women (from 20<sup>th</sup> weeks of gestational period) is 7 707 rubles, while for pensioners this minimum is 5904 rubles. Feruza found it difficult to understand which level of minimum subsistence she belongs to. Seemingly, she can count on only the lowest subsistence minimum mentioned in the decree, for the payment she receives from the government (which is 6517,62 rubles, if including the cost of natural social package and 5 635,99 rubles without it).

It is not easy to find a job for a non-disabled person, let alone a disabled person with visible disabilities. While looking for a job, some disabled people try to conceal their disability, but this was not possible for Feruza. At the department of employment of disabled persons at local job centre they sincerely wanted to help Feruza. They did not have any suitable vacancy to match her education and previous working experience at the time she applied there. Due to her disabilities they could offer only low-skilled jobs. Jobs that required work on computers such as a telephonist operator or medical clinic receptionist were not considered because of the problems with her eyes. The vacancies she was offered are as follows:

<sup>3</sup>

<http://www.rosmintrud.ru/employment/employment/322>, accessed on 14<sup>th</sup> November 2014

<sup>4</sup>

[http://www.gks.ru/wps/wcm/connect/rosstat\\_main/rosstat/ru/statistics/wages/labour\\_force/](http://www.gks.ru/wps/wcm/connect/rosstat_main/rosstat/ru/statistics/wages/labour_force/), accessed on 18th November 2014

1. Sales assistant at the newspaper kiosk. This was the first experience for Feruza and she could not explain to the employer why she could not work long hours, even without taking into account the time and effort for travel to work. Work shifts would deny Feruza the liberty to follow her regular schedule for insulin injections. She rejected the offer. A part-time schedule was not offered by the employer. Later she found out that she did not have to reject the offer, as a medical check-up prior to hiring would exclude her from working in such conditions.
2. Cleaner in a dental clinic from 07:00 to 14:00. After the meeting with Feruza, the employer said, "it's not an office, lots of work to do, with your hand, you will not be able to carry buckets with chlorinated solution; moreover, chlorine is very harmful after eye surgery". She made a record in the job centre's referral that satisfied everyone: the clinic, Feruza, and the inspector from the job centre. Any record in case of rejection to employ a candidate for a job is checked by the inspector from the job centre via telephone.
3. Cleaner at the school, 250 square meters area to be cleaned for a quarter of the minimum wage. The principal frankly said: "This is a school, kids play pranks, to clean for such a small salary is almost to work for free, this is a lot to clean, how would you carry buckets?"
4. Cleaner at the school again, the arguments are the same.
5. Cleaner in the office of a utility company that provides the city with heating. The job centre's inspector was counselling Feruza: "It is a rich company, they have hired a disabled with cerebral palsy as a yard-keeper, the young girl is glad about the attitude towards her and the salary, she even gets bonuses!" Feruza did like the office; it was clean and there were not many visitors. The company representative refused to employ Feruza: "We need a plumber, not a cleaner", having formulated his refusal as the absence of a cleaner vacancy.
6. Cleaner in the bakery, 750 square meter area to be cleaned. The human resource manager was indignant: "you won't be able to cleave ice in winter, how do they offer you such vacancy?!"
7. Porter (temporary) in a non-formal education organization. They refused with the statement "candidacy for consideration", when Feruza mentioned her upcoming hospitalization.
8. Matron at a private ophthalmological clinic. The clinic's representative met her with the words: "Actually, we need a cleaner, not a matron. We are forced to organize work position for disabled people. Wait in the hallway". She was on the phone and conducted negotiations for quite a long time. Meanwhile the cleaner was washing the white tiled floor, and Feruza was wondering if she could work instead of her. She was later called in and was told: "You have rejected to work, haven't you? I will record you this". Feruza was shocked. She had not rejected audibly, but wondered quietly why a rich company like this would change a vacancy position different from the one which was stated in the job centre data base. Feruza's said: "Sorry, I do not want to make a scene, but accuracy – the politeness of kings. Should I walk around with the voice recorder? I did not reject, but you rejected me".

This was the first time Feruza felt humiliated during her job search. She was emotionally

prepared to face an employer's refusal. It was enough to have a look at her and give her a couple of questions to understand that Feruza was not suitable for the sought position. Before the incident in the ophthalmological clinic, the potential employers tried to spare her feelings with their refusal and be diplomatic. However, the clinic representative did not just refuse her application, but blamed her for the refusal. The last record of the refusal had negative consequences for Feruza. Two refusals result in the suspension of payment of 977.50 rubles as her unemployment allowance. Employers should not be accused of inhumane treatment towards disabled people. First of all, the employer wants stability and a sense of duty from their employees. Often disabled people cannot guarantee such stability due to their health issues. Thus, the employers need to have back-up plan how to substitute the disabled employee if required.

So why could Feruza not find a suitable job? The Russian Federation determines not only the disability group scheme, but the degree of restriction to work, scaling from 'mild' (first) to 'severe' (third). In contrast, the disability group scheme uses different scales: from 'mild' (third) to 'severe' (first). Feruza received first degree of restriction to work, which includes the paragraph: "transfer to another job of much lower qualification in ordinary working conditions due to incapability to continue work by main profession" (MHSD, 2005). Feruza's experience to find a job showed that the medical-social examination board and potential employers views Feruza differently. There is inconsistency between the official evaluation of Feruza's restriction to work and her actual ability to work.

The Ministry of Health of the Russian Federation prescribes the criteria to determine the disability group in the corresponding order No. 535 (MHSD, 2005). Feruza was given Group 3 disability with no time limit. The criterion for Group 3 of disability is "violation of human health

with a persistent moderately expressed disorder of body functions". However, "moderately expressed disorder" can be seen by three categories: infantile cerebral palsy, traumatic injury of the median nerve canal, and poorly controlled diabetes of type 1 ('severe course' as recorded in the medical document) and visual problems (cataract and glaucoma). Taken separately, the afore mentioned health conditions are sufficient to determine disability. In Feruza's case, these conditions complicate each other. It seems that the integrated assessment of the candidate's ability to work has not considered medical laws and guidelines.

However, the authors did not aim to criticise the medical-social examination board of the Russian Federation. The disability issues exist in all countries and it is not uniformly easy for disabled people to attain the appropriate recognition. As the famous publicist of the Weimar Republic times, Kurt Tucholsky wrote: "The death of one man is a catastrophe. The death of thousand is statistics" (Tucholsky, 1932). One can paraphrase this as follows: the situation of one disabled person is a catastrophe, the situation of millions of disabled people is just statistics.

The analysis of Feruza's experience of disability assessment process and job search paradoxically demonstrates that the lower the education level of a disabled person, the easier it is for him/her to a find job. Highly skilled labour is not in demand and the disabled person must be prepared to leave a high flying career. The disabled person should maintain warm relationship with his family and relatives, as he cannot do without them.

The mercy of the individual towards disabled people depends on his moral principles, but the mercy of the whole society is determined by economics, not social morals. The well-being of the disabled person depends on the level of economic development of the country.

It is well known how hard and long it took to make the social model of disability to be employed not only among researchers, but

government officials too. The state ideology, no matter which paradigm it adheres to, medical, social or none at all, is not important, when it comes its attitude towards disabled people. The level of economic development of the country is more important. The social model of disability is a luxury only developed countries who can afford to support their disabled population. Disability is not a social problem, but purely economic.

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