VYING FOR A CHOICE:
GORDANA RAJKOV - A LIFE STORY

Translation of second amended edition

Edited by
Milica Mima Ružičić-Novković

Belgrade, 2020.

Center for Independent Living Serbia

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Milica Mima Ružičić Novković

Foreword:
A HALF-CENTURY BEARING WITNESS TO THE DEVELOPMENT OF THE DISABILITY MOVEMENT IN SERBIA

"…The disability movement is a mosaic movement for the 1990s. Diversity is its central characteristic. No one leader or organization can claim to speak for all disabled people. All social crusades are made up of people with complex and varying opinions. But today the black civil rights and feminist movements, in particular, are perceived as struggling with such diversity of thought and weakened by challenges to traditional thinking. The result is to diminish our appreciation of the enormous change each cause has brought about. Without one highly visible leader, the disability movement has gone largely unnoticed by non disabled people. But by its acceptance of differences, the campaign for disability rights forged a powerful coalition of millions of people with disabilities, their families, and those that work with them. People with disabilities have been a hidden, misunderstood minority, often routinely deprived of basic life choices that even the most disadvantaged among us take for granted. In the last twenty to thirty years, little noticed alongside the civil rights struggles of African-Americans, gays and lesbians, and other minorities, another movement has slowly taken shape to demand for disabled people the fundamental rights... It has led to the emergence of a group consciousness, even the start of disability culture, which did not exist nationally even as recently as the late 1970s" (Shapiro [1993]: 6-7).

The book before us testifies first and foremost to the individual actions and common steps taken by the disability movement towards the recognition and achievement of the right to make choices and decisions about one's life, the right to accessibility, personal assistance, sign language translation, other community living services and other fundamental human and civil rights.

Much has been written about the development of the disability movement in the second half of the twentieth century following enactment of the Americans with Disabilities Act of 1990 and changes to national legislation in the United Kingdom, Australia and around the world after three decades of advocacy to improve the position of disabled persons. The movement's impact gained initial global recognition in 1982 with the adoption of the World Programme of Action concerning Disabled Persons, and acknowledgement in 1993 when the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted. Five years ago, reflecting on the quarter of a century since the Americans with Disabilities Act had been signed into law, the movement in the United States and in Serbia took the opportunity to explore its legacy, which spawned greater access to information and a body of literature mapping the historical development of the disability movement.

Over the last twenty years, the Center for Independent Living Serbia (CIL), the "Lotos" Information Center for Persons with Disabilities from Tuzla, the organization for the protection of women with disabilities from violence and discrimination "...Iz kruga", the "VelikiMali" organisation from Pančevo, the Belgrade Muscular Dystrophy Association, the Association of Students with Disabilities from Novi Sad, the "Living Upright" Center, and others published independently or in conjunction with others, national research and translations of research, studies, testimonies and chronicles that contextualise and explain the different avenues of development taken by the disability rights movement which sprang up after World War II. In the US this was a time when young soldiers returning home from the war with life-changing injuries realised that society was creating obstacles that prevented some of its members from living freely, coupled with a belief that society ought to adapt to the needs of all its members (social model) instead of the prevailing belief that individuals should fall into line with society (medical model) (Shapiro, [1992] 2007; Barnes, [1993] 2012; Tatić, 2013; Ružičić Novković, 2014 and 2015) et al.

The medical model, and the charity model which it draws on, are modelled on doctor-patient and parent-child relationships. Society is divided into patrons and beneficiaries, i.e. objects of care, treatment or some other type of treatment and assistance. This division gives some the power to make decisions on behalf of others, which paradoxically, due an assessed or assumed dependence on the help of other people and engendered by (dis)ablism undermines those on whose behalf the decisions are being made and over time engulfs all aspects of everyday life. It can also be internalised, with both forms resulting in different forms of restriction and deprivation of the right to choose.

The social model, which is a legacy of the disability movement, implies the active and full participation of all in every aspect of social life, including the creation, use and assessment of the quality of support services as one of the equalisation measures (one of the legacies of the feminist movement). It steers us towards partnership as a primary link among people as bearers of equal responsibility for the development and use of common goods and services.

Gordana Rajkov's story testifies to the social climate and the development of the disability movement in the second half of the 20th century in the Socialist Federal Republic of Yugoslavia and its successor state Serbia. It further testifies to the development of the independent living movement in Europe at the end of the century and the intersection and impact of civil society movements on the development of independent living principles, which experience in organising personal assistant services has shown are applicable to all persons. It lends support to the phenomenon recognised in feminism that personal is political.

Backdrop to the book

In June 2015, the documentary *Semper spero* (Always Hope) was made using photos and footage from the archives of the (former) Muscular Dystrophy Association of Yugoslavia (founded in 1966) and the Muscular Dystrophy Association of Serbia, which looks at the emergence of the first organisation of persons with neuromuscular diseases in the Socialist Federal Republic of Yugoslavia and how that part of the movement evolved, as well as Gordana Rajkov's (leadership) role in these processes.

In November 2016 Gordana Rajkov celebrated half a century of active involvement in the disability movement, having worked in various fields, including having a hand in founding both muscular dystrophy associations. She introduced activists in Serbia to the concept of the independent living philosophy and set the wheels in motion to establish the Center for Independent Living Serbia which deals with this concept. Also, she is one of the first disabled persons to get involved in politics at the highest level and was the first disabled MP in Serbia in a tenure that ran from 2007 to 2012.

February 2016 marked the twenty-year anniversary of the Center for Independent Living Serbia, an initiative driven by Gordana following her return from Dublin (Ireland) where she contributed to the work of the Centre for Independent Living Dublin and the development of personal assistant services, a support mechanism based on personal experience and conditions for independent living (including housing) of disabled persons.

Based on her personal experience of independent living, her work in Ireland, and subsequent experience in assessing the needs of persons with disabilities, which she gained working as deputy head of the Belgrade office of OXFAM[1], Gordana Rajkov and her colleagues designed the first training programmes to raise awareness of discrimination and the rights of disabled persons, as well as a training and short pilot programme to enable them live independently in Serbia. The CIL forms the basis of current standards for the provision of independent living services within the social protection system.

In March 2011, the Social Protection Act was adopted in Serbia, which wrote into law for the first time the right to use independent living services, including the personal assistant service, in line with the standards and criteria proposed by the Center for Independent Living Serbia.

In April 2006, the Prevention of Discrimination against Persons with Disabilities Act was adopted, the first ever piece of anti-discrimination legislation in Serbia and the first to mention double discrimination against

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[1] OXFAM (Oxford Committee for Famine Relief) is a British humanitarian organisation for combating hunger based in Oxford, England, whose main mission is to combat hunger and which in the 1990s in Serbia, in addition to providing humanitarian aid, educated beneficiary groups about the basics of gender equality and the rights of disabled persons

disabled women. In the same year, the Planning and Construction Act was enacted, which requires all public facilities to be accessible.

In December 2006, the UN Convention on the Rights of Persons with Disabilities (CRPD) and Serbian National Strategy to Enhance the Position of Persons with Disabilities were adopted. Dr. Damjan Tatić, one of the founders of the Center for Independent Living, currently a member of the UN Committee for Monitoring the Convention, assisted in drafting both texts. Serbia signed the CRPD in December 2007 and ratified it in 2009. Meanwhile Serbia has harmonised most of its regulations with it. At the initiative of the European Disability Forum, the Center for Independent Living was tasked with managing the project that gave rise to the establishment of the National Organization of Persons with Disabilities Serbia.

Leaning on her experiences from her days at OXFAM, Gordana's work saw her be the first to broach the subject of double discrimination of disabled women in Serbia and incorporate gender dimension into work done by the Center for Independent Living and all its activities and projects. She also began to network with activists from the women's movement in Serbia.

Lepojka Čarević-Mitanovski (1963-2016), one of the co-founders of the Center and the driving force behind and founder of the organisation "...Iz kruga",[2] was responsible for ensuring that the position of disabled women was factored into all political decisions and resulting documents at the state level concerning health care and protection against violence, the rights of women and the rights of disabled persons in general. These included the Prevention of Discrimination against Persons with Disabilities Act in 2006 and Serbia's National Gender Equality Strategy Action Plan, in addition to shadow reporting on the implementation of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) which makes no mention of the rights and protection of disabled women. Also, one of the principles of the Convention on the Rights of Persons with Disabilities is the advancement of disabled women and protection from double discrimination.

Given that by virtue of the text of the Convention on the Rights of Persons with Disabilities this issue became relevant for the UN Committee for Monitoring Implementation of CEDAW, the organisations "...Iz kruga", Serbia and Vojvodina and Lepojka Čarević-Mitanovski set these processes in motion, including the development of the SOS hotline service and making other social and health services accessible to disabled women.

All these processes, in addition to amendments to the legislative framework which is now largely in line with the Convention on the Rights of Persons with Disabilities and with models of disability that see it as a human rights and political issue, are important because they were participated in fully by disabled persons, including Gordana Rajkov and Lepojka Čarević-Mitanovski.

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[2] Meaning "…Out of the Circle" (Ed.note)

Up until the turn of this century, experiences in advancing the position and rights of disabled persons were varied and obstacle-strewn. At the turn of this century, after a golden age for the movement and the adoption of a legislative package that advanced the position of persons with disabilities, from 2010 to the present, the role of the movement in Serbia has unfortunately been reduced to monitoring current processes and conforming to arrangements dictated by the authorities rather than monitoring and advocating full implementation of adopted documents and decisions.

Method and methodological innovation

With all this in mind, in December 2015, I suggested to Gordana Rajkov that we record her oral history in the same manner as the stories from the Oral Histories of Women in Vojvodina project run by the "Women's Studies and Research" Association in Novi Sad (ref. Bracić, Ružičić, Savić 2009: 28-30, Savić 2015: 504-511, Milinkov 2016: 75-81), a method which has been employed over the last fourteen years by the Center for Gender Studies at the University of Novi Sad where I am a doctoral student.

The plan was for us to focus on all those segments concerning personal experience and events that Gordana Rajkov bore witness to, played a part in and came to hear about and which are central to the development of the disability movement and her role in it and for the position of women, and based on the transcribed material, through shared authorship, to compile a book that would contain snippets of our conversation, passages from an authorised history published within the *Oral Histories of Women Politicians: A Silent Majority*, with permission from the editor (Subotički 2013: 206-232), with reference to the presentations to mark the jubilees of the organisations that Gordana helped to establish and develop, concluding with a speech given to mark two decades since the founding of the Center for Independent Living (at a ceremony held in Belgrade, May 5, 2016), on the European Day of Independent Living. Archive recordings and transcripts of her television interviews and public speeches would also be used.

"The oral history method is not only a rich collection of empirical material, but also serves to network and connect women of different age, knowledge, educational and life experience profiles, as a mechanism for exchanging personal experiences through dialogue with other women. The method gives them a platform to work together on the same project and to get to know each other while doing so, which later usually blossoms into friendship. In recording an oral history, women forge ties through mutual understanding and the strong emotional connections they create during the conversation." (Savić, 2015: (505). My experience of recording the conversation with Gordana Rajkov is further confirmation of this tenet. I recorded over twelve hours of conversation (February 15 and 16, 2016, in

Gordana's apartment in Belgrade). We finished up recording on May 19 by talking about her participation at the session of the UN Committee for Monitoring Implementation of the Convention where representatives from the Center for Independent Living and the National Organization of Persons with Disabilities of Serbia[3] presented the first shadow report on implementation of the Convention in the Republic of Serbia. Gordana supplemented the manuscript with accounts of events after May 19, 2016, as well as a look back at her work to raise awareness about the position of disabled women, her first-hand experience of temporary displacement after the May 1999 bombing of the street where she lived, the very end of the story, as well as part of the biographical timeline.

Through face-to-face conversations, phone calls, Skype calls and e-mail, we exchanged views on the method, access to information, and how they were to be woven into the story. The relationship we developed over our fourteen-month collaboration, the path it took, and the timely mentoring and strategic input from Professor Emeritus Svenka Savić to help bring the project to fruition, is one of my most treasured and profoundly impactful life and tertiary research experiences.

About the book

The book's title - "Vying for a Choice"[4] - is a line taken from Gordana's speech to mark the twentieth anniversary of the Center for Independent Living Serbia.

In the first part of the book (which looks at the roles of women and men in the first sixty years of the 20th century and the socio-economic consequences of the two wars that shaped the role of women in society and family), Gordana Rajkov recounts her mother's and father's experiences of cruel treatment in detention camps during World War II due to their political activities, forced labour during the wars, the poor living conditions endured by her artisan family, the influence of a multi-ethnic family (hailing from the Banat, Slavonia, Ukraine, and Austria) which, coincidentally, before and during the war, found itself in Belgrade, where she was born. She also recalls the different approaches to raising a girl and a boy; the birth of her brother; the differing expectations her parents had of her; the atmosphere at school; the onset of permanent chronic disease; the diagnosis and treatment in the early sixties of the 20th century; her rehabilitation in Fojnica and the emergence of muscular dystrophy associations at the federal and republic levels; the experiences of those who came to Fojnica from a non-institutionalised setting in which family was the main pillar of

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[3] Gordana Rajkov and Ivanka Jovanović (Ed. note)

[4] Video link to the documentary film making the 20th anniversary of CIL Serbia(English subtitles): https://www.youtube.com/watch?v=wyOx_EwzBsk&t=38s

support compared with those who came from a background void of support, which was the situation Gordana found herself in following the passing of her parents and her brother's enlistment in the Navy, after which he moved to Germany, visiting from time to time.

Beginning in 1965, when she met a group of children and young people in Fojnica who were in a similar physical situation to her, Gordana was always aware of the importance of working to improve the living conditions of persons with muscular dystrophy and disabilities in general and prevailing social circumstances. Her work is typified by a direct impact on systemic change, which she spoke of in both conversations: "...working in the disability movement I realised over time that even if you want nothing to do with politics, politics is guaranteed to find a way into your life, through laws, regulations and strategies passed by politicians, which affect how you live your life, with or without your involvement. Thus, as activists of the disability or some other movement, you have the choice either to get involved in politics and attempt to make your mark on it or just to sit and wait to see what someone else has in store for you" (Subotički 2013: (224).

"Only individuals can change the system. That's always been the case. All movements started with individuals. Neither the women's movement nor the black rights movement (I do not consider this phrase pejorative) started out with five hundred or a thousand supporters all at once. The women's suffrage movement was started by a handful of astute and dedicated men and women, starting with Susan B. Anthony to Rosa Luxemburg, as well as the civil rights movement and Rosa Parks[5], who was called the mother of the freedom movement...and Martin Luther King and a couple of confidants, or the disability movement spearheaded by Ed Roberts, Justin Dart Jr., Judith Heumann. These people have a vision of their own and advocate that vision and endeavour to motivate as many people as possible to row in behind that idea. Not all people will get involved, but the event itself, the knowledge - the understanding that by doing so you are having an impact on hundreds of people and their lives, whether they are cognisant of the fact or not, means in fact that you are having an impact on and changing [the system]" (p. 118).

Another side to Gordana's influence is the impact she has had on the lives of specific persons, be they service beneficiaries who find themselves starting out on an independent life, fundraising for evacuations during the war, responding wherever possible to minimise consequences beyond people's control, be they co-workers or close friends. Gordana's take on change: "People completely changed their outlook on life. They had new ambitions, they were

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[5] Rosa Parks (1913-2006) refused to give up her seat on a bus in Alabama on December 1, 1955, to leave an entire row free for one white passenger and move to the back of the bus where African Americans were required to sit. Historians view this deed as a catalyst for the African American civil rights movement, while her biographer (Theoharis, 2013) views it as merely one in a litany of deeds throughout her years of activism.

motivated to do something, to get involved in something, to continue their education, to start their own families. For example, Šaponjić[6], who was a service beneficiary, otherwise a wheelchair user, married a girl who was also disabled, and then they decided to move out of their family homes, were given an apartment by the municipality and lived together with the support of a female personal assistant and one male assistant. Our colleague Sveta[7] from Leskovac, who hadn't left his house in twenty years and was cared for by his elderly parents, suddenly got the opportunity to function independently and be able to do something thanks to the personal assistant service. He founded the Center for Independent Living in Leskovac, which he still runs today, and a few years ago he founded his own printing house: he became an entrepreneur! He built a small modern printing house in the yard of his house, and so now he takes care of his mother, who is still alive, instead of expecting the help of others. At one time, he was also a member of the Leskovac Municipal Assembly Council in charge of social issues and was to all intents and purposes involved in politics" (p. 91).

So far, 16 stories of disabled women who are originally from Vojvodina or have spent most of their lives there have been recorded (Bracić, Ružičić Novković, Savić 2009, one in 2013, two in January 2016 as part of the Gender Studies programme at the University of Novi Sad; professor emeritus Svenka Savić recorded a conversation with Lepojka Čarević-Mitanovski in 2001)[8]. All testify to limitations and neglect based on duality: healthy, worthy, powerful – unhealthy, unworthy, powerless; all in keeping with the applied principles of patriarchy and paternalism which I wrote about in *Ecofeminist Ideas in the Oral Histories of Women with Disabilities* (Ružičić Novković 2016: unpublished conference paper) and on ways to overcome, avoid, pay no heed to obstacles or tackle them head on and the strategic approach on a personal and general level.

Gordana Rajkov's experience is specific in that, through working and learning she moved into new fields and "broke down" the usual boundaries, learning quite early on the importance of international action to promote civil rights, specifically for disabled persons and women's rights, as has been my experience. Although she was vice-president and president of the Muscular Dystrophy Association of Yugoslavia, president and vice-president of the European Alliance of Muscular Dystrophy Associations (EAMDA), her role was equally dominant in both fields. She was the only woman in various settings and bodies crucial to the development of this part of the movement. In 1976, alongside her four colleagues, she was the only woman awarded the

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[6] Slobodan Šaponjić

[7] Svetislav Marijanović - Ceci

[8] Using the same method for her doctoral thesis on oral histories of female politicians, Dijana Subotički recorded the story of Vesna Škulić, a disability movement activist, a two-term (2003-2008) Social Democratic Party MP and advisor on persons with disabilities to former President of Croatia Ivo Josipović.

Order of Labour with Silver Wreath by the President of the Socialist Federal Republic of Yugoslavia for achievements at the Muscular Dystrophy Association of Yugoslavia. In addition, in 1986, by Decree of the Presidency of the Socialist Federal Republic of Yugoslavia, she was awarded the Order for Services to the Nation with Silver Rays for Special Merits and Achievements of Importance for the Socialist Development of the Country, the only woman, a person with muscular dystrophy, among the seven recipients.

Being in tune with developments in several concurrent or from a time point of view, kindred civil society movements, she identified the rules of the patriarchal environment and without openly changing it, she added to it or identified elements that could serve to further the position of disabled persons. These included: the topic of sexuality of disabled persons at an international forum in Belgrade in the late 1960s; where we should start when we decide to live independently (supporting Florence Dougal from Dublin on her pathway to an independent life); the impact on attitudes for assessing assistance needs, in situations primarily concerning personal hygiene needs and help with it, instead of trying to make people do it themselves, leaving them in constant danger of falling and injuring themselves. She also organised the first regional conference on the position of disabled women; insisted that several colleagues ditch their tracksuits for suits on a visit to the European Parliament and at a reception held by Serbia’s heir to the throne; influenced perspectives as to what qualified as a necessity for wheelchair users during the prolonged power outages throughout the NATO bombing campaign against the Federal Republic of Yugoslavia, etc.

In the foreword to the *Oral Histories of Serbia’s Female Politicians* Dijana Subotički writes that: “The stories of Gordana Rajkov and Sofka Vasiljković - both of whom have suffered double discrimination (one on account of muscular dystrophy, the other as a member of the Roma national community) and whose histories provide a behind the scenes look at what it takes to organise and develop associations of disabled persons, as well as the groundwork put in to ensure greater participation of the Roma population in public life and the formation of Serbia’s National Council of the Roma National Minority”. (Subotički 2013: 13-14).

However, speaking about the current state of play in the disability movement, which is perhaps the most important aspect of the book in terms of potential activism and studies going forward, Gordana Rajkov submits that: “[...] the movement is losing traction. The outlook is grim, I’m afraid we are on a tack towards the medical model again, which is disappointing”, adding that: “Organisations that are actually engaged in advocacy, that cooperate with local authorities and provide the best possible living conditions for persons with disabilities are thin on the ground. The main topic is how much money an organisation will receive for so-called programme activities. There is still not enough collaboration, there are numerous organisations with different points of view and ways of operating, which are often at odds with one another, intolerance among organisations is rife, proving counterproductive, while zeal to do something for the common good is waning. Exceptions to this are few and far between, not to mention volunteer work. Fewer young people want to get involved in organisations, which is a general problem globally, commonly referred to as the “benefit trap”. The more conditions persons with disabilities have that allow them to lead a normal life and work, the less incentive to get involved in organisations of persons with disabilities. This will pose a major problem in the future because when the older generations are gone, there will be no one to keep an eye on the situation and continue efforts to maintain and further improve the living and working conditions secured to date for persons with disabilities.” (p. 115). In spite of this, she believes that there are more young people who are ready to continue driving the movement forward.

From the point of view of language history, discourse analysis and anthropological linguistics, Gordana Rajkov’s narrative is valuable because it preserves the terminology and forms of address spanning both historical periods of her life and career (comrade, gentleman/lady). Also discernible is the parallel use of Serbian and English and the spontaneous use of English (code-switching) when recalling her time in Ireland and when quoting colleagues and friends whom she communicated with in English. The language transfer between the two languages is noticeable in the terminology used in connection with her time at OXFAM and after it. When signing-off on the manuscript, she placed quotation marks to convey the meaning of the *so-called* (*Granny was a “*bona fide *Austro-Hungarian”: order, work and discipline;”, such as (I learned at OXFAM that if you want to effect change, you have to choose people who will be “champions”, not those who find themselves in extremely challenging circumstances who would struggle to make an impact, leaving the more “tenacious” among them to effect change and continue to help others.*) or for certain names and terms that, from her point of view, are not in frequent use or are (were) not commonly known.

Conclusions

Bearing in mind that Gordana Rajkov is not alone in her views, the fact that in the meantime there have been shifts in activism and how people band together, the situation on the ground shows that we ought to syncretically take into account the experiences of all civil rights movements because their lack of knowledge about the purpose of other organizations’ goals and their disconnect is one of the reasons why the pace and acceptance of change has slowed and are not regarded as part of the same process, whose sustainability is important for all. That is why testimonies, the exchange of experiences and their analysis through this and related methods are relevant, in particular to ensure the general acceptance and full application of knowledge, experience, and tried and tested solutions inside and outside the system. The text of the oral history before us unreservedly spotlights this phenomenon.

Starting with intersectionality, analysis from the standpoint of social ecofeminism, cyborg theory and queer theory which are increasingly recognisable in the academic fabric of the disability movement on the American continent, as well as critical discourse analysis and other multidisciplinary approaches, the academic community has methods and tools at its disposal to, in particular, syncretise their tenets and outcomes and carry them over into the education system for sustainable development.

The social contribution of individuals, Gordana Rajkov included, without whose efforts and influence the topic of everyday life would still be off the table, a topic that today has an international dimension, necessitate us to take this approach.

This is the second book co-published by the “Living Upright” Center, the “Women’s Studies and Research” Association and Futura Publications as part of the series *Oral Histories of Women with Disabilities in Vojvodina.* This book was part of the project *The Role of Women from Vojvodina in the Development of Women’s Movement and the Disability Movement in Serbia,* which was supported by the Provincial Secretariat for Higher Education and Scientific Research through the competition for projects run by civil society associations in 2016.

The Center for Independent Living Serbia was a co-publisher and co-financier of the first edition. This second amended edition is published by the Center for Independent Living Serbia alone, which provided funding for this edition. This third edition of the book translated into English is also funded and published by the Center for independent living Serbia.

The book was translated by Justin Browne, who assiduously rendered Gordana’s idiolect into English with her full participation in the process and final authorisation. His choice to translate the story into Irish English (Hiberno-English) complements the method used – it is a part of Gordana’s shared experience from a period of her life when she lived and worked in Dublin.

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Gordana Rajkov and I have come together on this 15th day of February 2016, at her apartment in Belgrade to record her life story. We will discuss, perhaps not by chance on Statehood Day, Gordana's 50 years as a stalwart of the disability movement and its role in the development of civil rights in Serbia, which has not yet been examined from a historical perspective.

Having regard to the fact that Gordana's life story has already been partially published in the book "Oral Histories of Serbia's Female Politicians: A Silent Majority", edited in 2013 by Dijana Subotički, a PhD student in gender studies at the University of Novi Sad, we will incorporate passages of the published story, with permission from the editor, while the two of us will focus on topics not covered in that book, the history of the movement and her views on its evolution.

PART I CHILDHOOD AND EDUCATION

What was your childhood like?

I was born on 29 December, 1944 in Belgrade, immediately after its liberation, after World War II. That was a unique time in terms of what people had, in terms of scarcity, in terms of the way they could live. We were not a wealthy family. Both mam and dad were artisans - mam a seamstress and dad a shoemaker. When I was born, my mother was already quite ill because during the war she was involved in the partisan movement, she was arrested and taken to the concentration camp in Banjica, where she was severely physically abused, but she survived. Afterwards, they sent her to the forced-labour camp at Banatski Brestovac. My earliest childhood memories are of my mother's poor health. I know that as a child I was always afraid that something would happen to her because she suffered heart attacks which were extremely harrowing. Doctors gave her some drops...I tried to talk to her about what would happen tomorrow or next week, because it seemed to me that if we talked about something that would happen tomorrow or the day after tomorrow, then she would still be there.

Gordana, *1945*

I was born at eight months. Everyone thought I wouldn't survive, but here I am.

How did your mam and dad meet?

As far as I recall from the stories, they met at a dance. Back then the "Abrašević" Cultural and Artistic Society was open, and both were active members. Mam said she asked him: - Do you, Comrade, know the song "Šusti, šušti bagrem beli" /*Oh how the white acacia rustles*/ and that's how it started.

For the most part, my childhood memories come to me as small isolated bubbles of certain events, I don't remember anything in continuity, rather as individual events that come to me as a flash. Since my mam worked at home, she had her own sewing machine (an old Singer) that opened by unlatching a wooden lid, I usually sat on the lid while she sewed and I listened to my mam's stories or she taught me to sing old-town songs.

She usually talked about events from her childhood: where they went as children, for example, and she had one story that always gave us a laugh. My mother was the eldest of four children: a brother and two sisters, and a big gap between them. Her youngest sister was a just a whippersnapper when mam was working as a seamstress in some boutique. Mam told us how one Lazarus Saturday[9], when children always got something new, she sewed a coat for her and wanted to fashion a hat for her from the same material. And because the hat had to be ironed, mam put the hat on Aunt Vera's head and covered it with a wet cloth to iron the seams and shape it to her head. And of course, all hell broke loose because the steam started billowing out, the child started screaming, and granny arrived on the scene and said: - Are you out of your mind?

You come from a revolutionary background?

My mam was involved in the Yugoslav Resistance Movement against the Nazis, as part of a small contingent of women and she was quite active politically: that was my mam's family: granddad was also in that movement. He was arrested and sent to the concentration camp in Banjica, where he was executed. So, I never met my granddad on my mam's side, and my dad's dad, my other granddad, perished in the First World War.

I remember her saying how many of them were beaten in that concentration camp in Banjica. My granddad was in another part of the camp at the same time. Prisoners were occasionally allowed to walk around the prison yard and they communicated with other prisoners on the first floor of the building in some kind of sign language to enquire who was who, what's the latest... I remember my mam talking about how my granddad, the day before he was to be executed, said that the previous night he dreamt that a plane had landed in the yard of the camp. In this dream, my mam sat into the plane and took off while he stayed behind. He then said to her: - You're sure to get out of here. Look after mam, your sisters and brother! And the next day they shot my granddad. I always wondered what that prison yard looked like and what those windows from which they attempted to communicate with the people downstairs looked like, because she was housed on an upper floor.

Did she talk about who beat them?

Well, our investigative police. The chief of police was the notorious Bećarac. Mam was reported by her bridesmaid because someone noticed that

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[9] Lazarus Saturday - an Orthodox religious holiday, eight days before Easter (Ed. note)

several women were meeting in their apartment at the time, including mam's bridesmaid, and reported it to the police. Then they arrested and interrogated mam's bridesmaid, and after a couple of slaps she said: - I don't know the names, but she[10] knows all the names of the women who were there because she arranged it. And when they arrested my mother they beat her and said: - You have to give us the names of those who were there? Mam's response was: - What kind of friend would I be if I betrayed my friends. And then of course they just continued to beat her because they realised that she wouldn't fess up, so they beat her until she passed out, and when she woke up the next day, they gave her more of the same...She fell extremely ill from those beatings. Granny barely succeeded in having her let home to die and it took her several months to get back on her feet and to be able to do a few bits.

My granny was born in Slavonia, which at that time belonged to Austro-Hungary. Granny was a "bona fide Austro-Hungarian": order, work and discipline. Very stand-offish with everyone. Everyone addressed her using the polite/formal form of "you"[11]. Even us kids. Granny would put the fear of God into you because when she came to the house everything had to be tidied away, the dishes had to be spic and span. My mam was physically alike to my granny, yet she was different: warm in nature, quiet, very patient; traits she probably inherited from the other side of the family. My maternal granddad was a Russian (Ukrainian) from Kiev who settled in Serbia after the Balkan wars.

My uncle was a member of the Yugoslav Partisan Resistance Movement which fought against the Nazis and blew up warehouses and everything else, just like in the television series "Otpisani"[12], and one aunt was in the partisans. She survived the Igman March, fell ill and was unable to bear children. So my mam's whole family was politically active, and I remember that youngest aunt saying (because she was a child at the time) that when they would come to make enquiries she served them drinks and tried to hide her disdain, mounting her own form of resistance in doing so.

Dad's family was apolitical. So, we had this strange dynamic at home: a mother who was the secretary of a party group after the war and a father who came from an Orthodox family, not particularly religious, but still all traditional holidays were respected. Saint Nicholas was celebrated, which was the family's patron saint, as well as Christmas and Easter. I don't know where the stories come from that there was a ban on celebrating religious customs. You could celebrate at home, it was up to you and there was no ban as such because I know for a fact that my brother and I went to church with my dad on the mornings we celebrated our patron saint's day, and brought to church saint's

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[10] Gordana's mother

[11] In the Serbian language, depending, among other things, on the person you are addressing, there are two ways to say *you*, an informal and formal way. It is commonplace for children to use the formal way when addressing their elders.

[12] "Written off" - Legendary television series about resistance fighters during the Nazi occupation of Belgrade during WWII.

celebration cake to break, and boiled and sweetened wheat with walnuts to be consecrated. That's how I grew up too. I was never religious, I never believed in God, but I loved those customs and loved it when my mam made patron-saint-day cake. Mam kneaded the patron-saint-day cake, and the dough was used to adorn it with braids or little birds. I had the job of rinsing the rice, and when we'd find those tiny little black grains in the rice, we kept them so that when we made the patron-saint-day cake we would have eyes to put on the birds. At Christmas time it was customary for Santa Claus to bring children presents: you left your shoes in the window in the evening, which had to be polished to the perfection, and during the night Santa Claus would come and leave presents. In the morning when we'd wake up, we'd rush to the window to see what was in our shoes. And, of course, mam and dad always bought something practical: socks or the like and put them in the shoes. There was no chocolate or sweets back then, instead you'd get something practical. Mam made her own sweets by caramelising sugar and then pouring it onto a marble slab that stood on the stove (of course, the stove was wood-burning), then diced it using a knife and when the sugar cooled it hardened and you could break it off into sweets. Those were the sweets we had back in my day.

There were rules to adhere to. If guests came, if adults were in the room, you had to go outside because it wasn't your place to sit there and listen to what the adults were discussing. They'd give you a stern look and you knew what to do. And when you'd go to visit someone at their house and they served cakes and the like, you'd first glance at mam or dad for permission and only when they gave the nod could you take a cake. So, I had a strict upbringing. That's where I picked up granny's ethos: order, work and discipline. My mam was never as strict as my granny, but nevertheless I never learnt to show tenderness and to this day I remain a rather rigid person, I'm accustomed to holding feelings back. I can do anything for someone to show that I care about that person, that I love him or her, but I rarely express that verbally. I'm not used to outpourings of tenderness, that's how my childhood went.

Mam and dad

Dad was born in Bešenovo, Vojvodina, and then the family lived in Kikinda for a while and then moved to Belgrade from Kikinda. My granny remarried a widower who already had children when my dad's dad died in the First World War, which brought them to Belgrade. My mam's family lived in Croatia, in Slavonia. Granddad and granny had decided to go to Kiev because granddad Nikolai Gromiko hailed from Kiev. They packed up everything they had and came to Belgrade to continue their journey. However, that day, or the day before, a state of war was more or less declared and they couldn't leave the country. My mam said, at that stage only my uncle had been born, that she was resting on some suitcases* at the train station and cradling that uncle while my granny and granddad were trying to find a way of getting to Ukraine. So not being able to leave the country they went to Zlatibor and worked in a hotel there: granddad as a waiter, and granny as a cook. Granny was a housewife, maybe she'd received some basic schooling available at that time because she was orphaned when she was five years old. Her mother died and she stayed to live with her father. And when she turned six or seven, she went to work as a day labourer. It was commonplace to go to wealthy houses and do a bit of work there, like gathering wood or whatever children could do. She too grew up in a family void of any love and attention, tenderness, in dire conditions, and she passed down that ineptitude to show tenderness to her family. Being from Slavonia, famous for its cuisine (and, of course, she'd mastered all those skills), she got a job as a cook. And my granddad got a job there as a waiter. They returned to Belgrade from Zlatibor and granddad continued to work as a waiter, and he was also a card-carrying member of the Catering Workers Trade Union. Mam worked as a seamstress in a boutique because she had completed a sewing apprenticeship. At that time granny had stopped working because they already had four children, so she was at home. After the war, my mam continued to sew and had her own "clientele". My mam said that after a piece was finished customers usually let her keep the leftover fabric, the so-called offcuts, so my mam used them to sew me dresses, skirts, blouses... She had sublime sewing skills and could fashion new clothing from practically anything. She made alterations to coats; I bought my first coat when I enrolled in university, but up to then I always wore coats that were reshaped for me and looked like new.

Dad made my shoes. I recall one Lazarus Saturday. My aunt on my dad's side was an embroidery machinist, and one Lazarus Saturday mam was left with a piece of some pink taffeta so she made me a dress out of the taffeta, and my aunt embroidered blue butterflies on the dress. My dad made me pink shoes, which I still remember today. But they didn't tell me it was for me, instead my mam told me that some customer had ordered it for her little girl. And then she measured me up, and I had to stand on the table so she could measure and take in the hem, etc. I kept saying: - Why do you keep hounding me to try it on when it's not even mine!

And then on Lazarus Saturday mam said: - Come on, put this dress on! Back then children wore knee-high lace stockings, and those pink shoes and I said: - I'm not wearing something that isn't mine. Only then did they tell me it was mine, that they'd made it for me. I have that childhood

Gordana with her brother and granny celebrating Lazarus Saturday memory - with that pink dress and a huge bow resting on my head.

Do you remember, although it's probably just minor detail, if pink was as important then as it is today in distinguishing girls and boys?

Very much so. It was the same when babies were born. I remember my mam telling me that when I was born children were swaddled like mummies using sheets embroidered from a coarse material up until they were I don't know how many months old, and that my sheet was pink embroidered with flowers and my mam kept it safe for a long time.

When was your brother born?

He was born a year and a half after me, in the summer of forty-six. We were like chalk and cheese! He was terribly restless. On top of that he wasn't particularly fond of school, he wasn't very obedient... so dad would punish him often and I know that my mam tried to defend him.

Did your mam and dad get along?

They did, by and large. There were no quarrels in the house.

Did you have a sleeping area separate from your parents?

Yes, we had a two-room apartment. There was a kitchen which led to two rooms, with the room at the end facing the street. It was one of those old Vojvodinian houses. It fronted two streets: Ohridska street, as it is still known today, and Krušedolska street. First, you'd enter a passageway that brought you into a courtyard with apartments on all sides. And on the other side, across the street, was the small Church of St. Sava (where I was baptised). On that side of the courtyard was a fence covered in hedge bindweed and a gate tied shut with rope. We paid rent there, and in the same courtyard, only in a separate building, my paternal aunt lived with her husband, daughter, and granny on my dad's side. We thought their apartment was the bee's knees because it had a toilet inside the apartment, whereas we had a toilet in the courtyard. So, in winter you'd be frozen alive by the time you reached it.

And what kind of relationship did you have with your relatives?

Well, perfectly normal. We'd play in the courtyard, go to my aunt's. My dad's whole family lived there. Dad's older brother went missing during the Second World War, somewhere in Germany in captivity, and they never found out what happened to him.

Your mam had a younger brother and two more sisters?

Yes. Being a male child, my uncle was always put on a pedestal, everything played second fiddle to him. My aunts were fantastic. The middle aunt was one for “divilment” and I was the only one in the family who addressed her using the informal form of “you”. The youngest aunt was magnificent: quiet, peaceful, and a ballerina. She performed in the theatre at Terazije. Her name was Olivera, known as Vera. When she stopped performing, Aunt Vera continued to take me to the theatre frequently and would introduce me as her daughter. Later, she met my uncle who was a lawyer and he persuaded her to enrol in a vocational school for social workers because life as a ballerina was no walk in the park. He also enrolled in the vocational school for social workers even though he had graduated from the Faculty of Law, out of solidarity with her so that it would be easier for her to study and finish school. They both worked, my aunt as a social worker, and my uncle as a lawyer. Uncle was a charming man, dark-skinned, tall. A wonderful man, I adored him. I loved spending time with him. And because I addressed my aunt using the formal form, I of course addressed my uncle using the formal form too. And then they kept on at me to stop addressing them using the formal form and to use the informal form of “you” instead. There was even a rule when I made a slip of the tongue, I can’t remember what I had to do, but there was no chance of me sticking to it and for the rest of their lives I addressed them using the formal form of “you”.

My mam’s name was Juliana Hefinger. When she got married, she changed her religion because she was a Catholic, and took another name, Snežana Rajkov. So, the people who knew her from the time before she got married, and her family, called her Julka, and for those who met her later she was Snežana.

And did your aunts change their names through marriage?

No, because they already had Orthodox Christian names and when they got married they changed their names, as in they took their husbands’ surnames. Granny was named Elizabeth Hefinger and after she married granddad, who was Orthodox - Nikolai Gromiko - she also took an Orthodox name and became Marija Gromiko. Such was the custom.

Do you know how they met?

I don’t. They lived for a while in the village of Stari Mikanovci in Slavonia. That’s where they met. They were chalk and cheese. Granny was tall, slim, a striking, beautiful woman. They say that they called her the beautiful

Lisa in her youth, while granddad, as a Ukrainian or a Russian, was cut from an altogether different cloth. He was short, blonde and cheerful. They say he was fond of dancing the Kozachok[13] on the table after he'd had a few drinks. I can just imagine what that relationship looked like: Granddad up on the table dancing the Kozachok and granny staring daggers at him.

Did any of the Ukrainian and Russian culture rub off on you?

No, because my granddad had already passed away by the time I was born, but the youngest and the middle aunt looked more like my granddad. Mam and my uncle looked like granny, tall and slim, while those two aunts were shorter and blonde. My mam was brown-haired, and they had more of a Slavic, Russian look to them. And with that great big Russian soul. I'm a strange mix of the Austro-Hungarian and the Russian temperament: a sensitive and warm Russian soul "trapped" in a rigid and cold Austro-Hungarian plate of armour - order, work and discipline. And to top it all off, the Serbian temperament because I grew up in Belgrade.

What kind of interaction did you have with your peers at the time?

I've always lived here in Vračar[14] near this old small Church of St. Sava and we spent our childhood days playing in the streets. We played rag-ball, made daisy chains and other bits and bobs until we started school. So, I was no different to other children and played in the streets. When you'd get hungry, you went home and there'd be a treat waiting for you: you'd get a slice of bread and fat covered with bell peppers, and you'd take it with you back out onto the street and eat it. school.

What school did you go to?

"Saint Sava's" primary school[15]. It's there next to the Temple of Saint Sava. Another wing was built on at a later stage. I think the school has the same name today. Later they built on another wing, which was a school that went by a different name.[16] I remember my teacher, she was really a great woman, not overly strict, and she treated us as if we were her own, and given my strict upbringing at home I was always an excellent student.

And did you receive a preschool education?

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[13] Kozachok - traditional Ukrainian folk dance (Ed. note)

[14] Vračar is one of Belgrade's municipalities (Ed. note)

[15] Primary school lasts eight years (from 7 – 15 years of age) (Ed.note)

[16] The primary school "Djuro Salaj" moved into the building erected in 1958. These two schools were amalgamated in 1972 as "Saint Sava's". (Ed. note)

No. There was no such thing at the time. I don't know if there were any playschools at all because women were usually housewives. And if the mothers weren't housewives, if they were wealthier and came from such families, then the children had governesses who looked after them.

What other childhood memories do you have?

Gordana with her mother, 1949

One of my childhood memories is that we were an extremely poor family. In summer, my mam used to take us to the famous "Orač" tavern for kebbabs, which used to be on JNA Boulevard in the direction of Slavija. My mam was able to rustle us up lunch out of thin air, and with that Vojvodina cuisine being so diverse, one chicken used to last a week: she made soup from giblets, she used the wings for chicken stew with dumplings, she dusted drumsticks and thighs in dunst (saute), breaded the white meat, all served with a side dish. So, for four days straight there was just chicken on the menu. That was for us: dad and mam ate what was leftover. Dough was a staple ingredient, we called it "nasuvo", which is actually dough with potatoes. My mam kneaded those square noodles herself; she never threw away the water used to boil them but used the water from the noodles and potatoes which always had pieces of dough floating about to make red pepper soup. Pottage and "nasuvo" and that was your lunch. So, to be honest, when the sanctions were in place in Serbia[17] I was more concerned about hygiene than food as I'd always manage to rustle up something out of nothing.

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[17] During the Yugoslav Wars of the 1990s and early 2000s, several rounds of international sanctions were imposed against the Federal Republic of Yugoslavia, which consisted of the Yugoslav republics of Serbia and Montenegro.

When did the symptoms of dystrophy begin to appear?

I was diagnosed with muscular dystrophy when I was in primary school. Between the ages of eleven and twelve they noticed that I was walking oddly and that I was finding it harder to do gymnastics. I recall that my dad constantly gave out to me because I somehow shot my legs out from my knees when I was walking, and he thought I was fooling around. He kept saying: - Walk properly, stop walking like a castrated horse! Then, finally, the PE teacher referred me to the Neurology Clinic where the famous professor Jovan Ristić practised and he diagnosed me with muscular dystrophy. Back then there was a strange approach to it. As a result Professor Ristić ruined quite a number of children because the theory was: you have a disease that causes muscle degeneration for which there is no cure. The more physical activity you do the sooner the muscles will degenerate and you'll be left without the use of them, so you'd be better off resting. He suggested to my mam that she pull me out of school. My mam found it preposterous that she should take her child, who was full of beans and an excellent student, out of school to mope around the house. Seamstress or not, it didn't make sense to her. Of course, she let me continue to go to school. Thanks to my mother's persistence I finished school, but there were a lot of families who heeded the advice of the experts and took their children out of school. Naturally, the muscles still deteriorated but only faster because of their sedentary lifestyle spent sitting at home, and they were left without school, without an education, and without muscles.

She went to great lengths to take me to various doctors who were rumoured to have some form of treatment. I remember that one of her customers was a lady whose cousin lived in Vienna attached to some diplomatic mission and that she took me to Vienna to attend some renowned clinic to see if anything could be done. Then she took me to the Rebro Clinic in Zagreb to see Dr. Žeškov, who was illustrious at the time. My mam made sure that I didn't miss too much school because we attended doctors and hospitals during class time. I went for a check-up every two months, for example. Mam always went with me. We'd go by train, board the train in the evening and then travel overnight. We'd arrive in Zagreb at dawn and then wait for the tram that went from the train station to the Rebro Clinic and wait for the doctor there. The analyses were completed by the afternoon, two or three o'clock, and we'd travel home the same day the same way. Then we'd go back to the train station, hop on the train and we'd get home late at night. But I remember that station restaurant where we usually went for lunch. It was one of the rare occasions that we had lunch outside the house. If we had a couple of hours to spare we'd take a stroll through the centre of Zagreb, ride the funicular, and go past the theatre...

Has anyone in your family had dystrophy before you, or are you the first?

No, not that I'm aware of. Now, who knows if some great-grandmother or someone else had the disease. It's an interesting question. I have facioscapulohumeral muscular dystrophy, which can be hereditary but can also leapfrog several generations.

What were your other interests besides school?

I was a member of a folk-dancing group at the "Branko Cvetković" Arts and Cultural Centre and was an active child. I started learning folk dancing very early because my aunt on my dad's side was a member of the "Branko Cvetković" centre, and her daughter, my cousin, was a folk dancer, then the pioneer section was formed, and then I joined the pioneer section because I liked to dance. She took me to rehearsals, I'd watch them dance and change into different costumes... and so I joined the pioneer section. Beside the old Church of St. Sava there was a wall eight to ten centimetres thick with acacias growing there. I was forever climbing that wall and falling off it, and the priests used to chase us around. We played hopscotch in the churchyard because it was paved with flagstones grouted with tar which meant you didn't have to draw the boxes, just write the numbers.

The most popular games were hopscotch, then elastics, then skipping, and red rover[18]. Five stones... Oh how I loved to play five stones... You've to look for pebbles. They had to be as round as possible, the same size, white...and everyone jealously guarding their stones. So wherever I went, my pebbles went, without fail. Now they were proper games!!! There were no other types of games, nor anywhere near as many books and toys for children as there are now. I don't remember having any toys, maybe a few rag dolls.

What did your schooling look like?

Primary school back then lasted first for four years, then four more years at "St. Sava's", to complete elementary school (8 years in total). After that, I enrolled in comprehensive school (*gymnasium*). I went to the Fourteenth Belgrade Gymnasium beside The Vuk Monument in Belgrade.

Had you a particular interest in any of the subjects in primary school?

Well, no. I liked to study and I was probably better at natural sciences such as biology, physics ... that's how I ended up taking the natural sciences track in comprehensive school. We had far more classes in mathematics, physics, chemistry, while Latin was mandatory for the first two years, with a

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[18] Children's game popular in the late nineteenth century. (Ed. note)

smidgen of philosophy, history. Those who took the social sciences track had subjects that we didn't have: music, then art, and they got to listen to classical music in class. I remember there were slide projectors (an ancient piece of equipment), so in those art classes they learned about painters, architecture, trends in architecture, which I always felt cheated of later in life.

Gordana (second from the left) with a group of pioneers being received by Yugoslav President Josip Broz - Tito on May 25th, 1955 (Youth Day)

Were there any art secondary schools back then?

I don't know, I'm not sure what art schools there were. So, for example, I know that there was a ballet school and a music school - both secondary-level schools, and some of my friends, for example, Jelena Jovanović (Šantić), a famous ballerina who founded Group 484 after refugees started arriving from Slavonia and Baranja, she went to that secondary ballet school and to comprehensive school. I felt deprived of that knowledge of art, even of history, because we had far less history classes than those in the social sciences track. Later I tried to make up for it by buying piles of books on art history, music encyclopaedias and more.

Did you mingle with your peers in the different tracks, were there any combined classes?

No, there were no combined classes, but the track departments were next to each other at the same time so you'd meet at break time, but again, you hung out with whoever you wanted.

Are you still in touch with any of your friends or classmates from primary school?

Well not anymore. I went to primary school with half of those who later went on to study, that is, who took the natural sciences track at comprehensive school. For instance, I knew Klara Mandić from primary school. I went to school with her, including Gymnasium; however, we stopped hanging out after that.

Do you remember any of your friends from that period?

I remember a lot of those I went to comprehensive school with. Afterwards, Klara Mandić got involved in social and political issues, while several later graduated from university and became doctors.

What percentage of students in the class went on to university?

A remarkably high percentage. Almost everyone went on to university. I remember Bobica who finished medicine and was a famous radiologist. And Boba Stefanović, who also finished medicine and went on to be a renowned professor at the university, now retired of course. My best friend at the time, Slobodanka Živadinović, we called her Žiži, went on to teach mathematics at the Tenth Belgrade Gymnasium. In fact, I studied mathematics because of Žiži, for completely prosaic reasons, because I really liked physics and I wrote my secondary-level graduation paper on physics: the solar spectrum, decomposition of the rays...and I wanted to study nuclear physics. At that time, it had just been introduced as a subject at university. And since I had already fallen ill at that stage my mother was horrified because to her nuclear physics sounded like some kind of radiation and she didn't support my choice on account of my health. I was decent at maths but it wasn't my forte. My friend Žiži visited the faculties to see where the entrance exams were held and to find out which of them received the most applications. On the back of that she discovered that no one applies for mathematics and that you could enrol in that department of the Faculty of Natural Sciences and Mathematics whenever you want, without having to sit an entrance exam. Then she found out from somewhere that there were only three or four subjects in the first year. So, she decided to enrol in mathematics, and as I couldn't enrol in physics, I too enrolled in mathematics. The Faculty of Natural Sciences and Mathematics still stands where it has always been, near Studentski trg. The mathematics track was on the fourth floor, and as my illness, dystrophy, progressed, it became increasingly challenging for me to get to the fourth floor and back down. The building had an elevator, for professors only; however, I sometimes managed to get my hands on the key to the professors' elevator and go upstairs. But I endured those four years nonetheless, and in the meantime, I also fell in love with maths.

And besides accessibility, did you need any other kind of support then?

No, I was able to function on my own. The only problem was that due to the nature of the disease I fell frequently, then my spine started to arch, lordosis set in and mobility became increasingly problematic for me.

In maths, was there any branch that interested you the most?

Yes, there were two branches. One was for future teachers of mathematics in schools, and the other was computer science. It was akin to applied mathematics, which I found more interesting, and I enrolled in that course. We did an internship at some institute, somewhere down the road from Terazije, which housed the first computers, huge machines that took up half a room and worked on a binary principle - the forerunners of today's computers, laptops...

There were about twenty students in my department. In fact, there was an equal number of female and male students. At university I mostly hung out with my friend Žiži with whom I'd enrolled in mathematics. It's amazing really but other than her I don't remember anyone else in particular from my university days. I remember my friends from comprehensive school much better. Maybe because most of us went to primary school together and then we'd meet at graduation reunions. In a way, people were closer to each other back then.

In comprehensive school Žiži and I were, I think, the only ones from working-class families. Most of the students were the children of engineers, doctors...Back then all the pupils wore dust-coats with embroidered and crocheted collars so we were all equal in school. The dust-coats were black with white collars.

Did you have a crush on anyone at the time?

Well, not before the end of comprehensive school. Just before we left comprehensive school, I think we'd probably finished the fourth grade, Žiži and I went to the cinema in Zvezdara, to the garden. There were a few guys hanging around and I met a guy. Now for the life of me I can't remember his name, but he was the first guy you could say that I dated. He'd wait for me on the corner, and my mam would stand behind the window curtain to check who I was meeting with and where I was going. And, of course, I had to be back home by a certain time. No later than ten o'clock.

Did he go to the same comprehensive school as you?

He was a couple of years older than me; I think he'd finished school by then. It was one of those teenage summer romances. I enrolled in university at the end of that summer. I don't even remember his name.

And any love interests at university?

Well, I had a boyfriend of sorts at university who I was in love with and we dated. He was at the tail end of an economics degree when I enrolled and that's how we met. We went to dances and all the rest. Dances were held at the "Ivo Lola Ribar" student residence near The Vuk Monument and at the "Tesla" mechanical engineering school at Narodni front street. After the new Faculty of Electrical Engineering opened dances were also held in the faculty's entrance-hall. In the winter when you'd go to dances you took your shoes in a bag and switch into dancing shoes when you got there. I'd say I lived just as anyone else my age did at the time; the only thing was I had a harder time getting about.

Later, I had two serious relationships, when I was madly in love and loved. The first lasted a long time, about ten years, there was a fantastic chemistry between us, and we complemented each other very well: he was one very capable and witty man. The romance had gone out of our relationship, which fizzled out after ten years, maybe because we lived in different cities, but we've remained friends to this day and I'm still in touch with him from time to time and use him as a sounding board. I trust in his judgment, which is always underpinned by good intentions.

And my other great love lasted for about five years but it ended tragically when the man I loved died suddenly and unexpectedly. He was a wonderful man, a true intellectual, highly educated and with a special sense of humour. We got along famously. It was a massive blow for me. He suffered a heart attack at the tender age of thirty-two. I was severely depressed for two years. It was a very hard time for me. The very thought of his name had me in tears. Since he was also involved in the Muscular Dystrophy Association we went to rallies together: everything I did evoked memories of him. We had plans to settle down and have a family. Who knows what my life would be like today if, sadly, he hadn't passed away. Everything we'd planned for our life together vanished in the space of a day. After the death of my dad and mam (which is inevitable at some point as nature takes its course), that was my first major loss, one that changed the meaning and course of my life.

After that I didn't have any serious relationships, so, regrettably, I didn't get to have a family of my own. That remained my great unfulfilled yearning...

When did your dad pass away?

Dad died when I was seventeen. He fell ill suddenly. They thought he had tuberculosis so they sent him to a respiratory resort, only for it to transpire that he had lung cancer and six months later dad died at the clinic where the neurology clinic stands today. And mam, who was already in poor health, suffered a stroke from the shock of hearing that dad was ill, that he wouldn't pull through and that he only had a few months to live.

I was still in comprehensive school at the time. I remember that dad was in hospital and that I came home one day and mam wasn't there and my aunt said she he'd suffered a stress-induced brain haemorrhage and that she'd been taken to the Internal-Medicine Clinic B. The building is across from the

Neurology Clinic. She couldn’t speak. It was very upsetting...Mam was in very poor shape because she’d lost the use of her right arm, leg and lost her speech and since she was seriously ill, she was in a very critical condition. After that we kept a vigil at her bedside and tried to decipher what she needed by using facial expressions...Then I’d go to school in the morning, and in the afternoon I’d be with my mam, and then I’d go home in the evening and my granny would take my place. Dad passed away in the meantime, sometime in late October. The biting winter weather had already set in and the street that the clinics were on was largely deserted, void of passers-by in the evening. The street lighting came in the form of two poles, one on the left and one on the right of the street, connected by a wire with a light bulb suspended in the middle like a lantern. I used to make my way home down that street at eight in the evening with the wind howling and the streetlight swaying, casting shadows. And then I’d have to walk past that hospital where my dad died. Well, it petrified me, and I don’t know why. I was always in a hurry to get that part of my walk home over with and reach the boulevard where there were trams and people. But that journey home from the clinic in the evenings, the walk down that street, and the streetlight casting shadows still haunts me.

Mam recovered: she was a real warrior. She was made of sterner stuff, although you couldn’t tell by looking at her. When she got out of hospital, she walked with the aid of a cane, wore a sling so that her arm wouldn’t droop, and her mobility was severely restricted. Although I used to go to the market to help her prepare food and clean the house, once her health took a turn for the worse I took over the housework. In fact, she never fully recovered but she could walk with that cane and do bits and pieces and communicate. So, I finished comprehensive school and enrolled in university. I was finishing up my first year of university, I remember studying for exams and heading to bed one evening because I had to be at university early in the morning, when mam came in, sat on the bed and started caressing my head and kissing me, which was totally out of the blue and hadn’t happened before. And then I said: - But, mam, I have to go to sleep now because I’m up early in the morning to sit the exam. She died that night. I have no idea how. Basically, when my brother came home at about ten or eleven o’clock, he found her in the bathroom. So, she too passed away suddenly. I was a little over nineteen when I was left with just my brother.

It wasn’t until much later that it dawned on me that there was a resemblance between the moment my granddad had a premonition (dreamed) that he was going to pass away and mam’s behaviour but I failed to make the connection at the time. She was actually saying goodbye to me. My brother and I took it very hard: our aunts, granny, neighbours congregated at the house...A woman slept over with us and observed some arcane custom of covering all the mirrors with sheets. The house looked eerie. A ghost house. Those white sheets draped all around the place. After the funeral we came home and a big crowd gathered where a spread of food prepared by aunts and neighbours awaited.

That was one of the most difficult moments for me because when people don't see each other for a long time, save for such occasions, they pull up a seat and start chatting about their families, and you don't know whether you're coming or going. I remember I left the house, went to the park, and sat on a bench. I sat there until I thought they had left. My mother died in June of sixty-two.

Life after mam's death.

By September of that year my brother had left for the army. He joined the navy in Split, which at the time entailed three years' mandatory service. So I was left completely to my own devices, without my mam, dad, and brother, for the duration of my university years and thereafter. While he was serving in the army my brother never came to visit and he rarely wrote. And until I got the family pension, I had no livelihood, and then I rented a room to a married couple to make ends meet.

Afterwards, I received my mam's pension. That helped me get by somehow. I learned to save and to handle money prudently.

PART II
ACTIVISM

When did you meet other people with muscular dystrophy?

Almost right up until my mam's death I was convinced that I was the only living being with the disease despite having witnessed young children with muscle diseases at the clinic in Zagreb, but I never associated that with my condition. And then my mother made the acquaintance of Olivera Jandrić somewhere. She was the forerunner of the muscular dystrophy activist movement. She had spinal muscular atrophy, the most severe type - she never walked. She lived with her father, stepmother, and aunt Janja, who dedicated herself to her and constantly cared for her. I remember that my mother and I were standing once at the street window, you know just like they have in those houses in Vojvodina, at the bay window, and that aunt Janja and Olivera were walking down the street and then my mother said to me: - That girl has the same disease. So she was the only person I knew of that had this disease.

I was still studying when in 1965/6 an article appeared in the Zagreb weekly "Arena" that a doctor by the name of Geza Čeh at the general hospital in Zenica was treating muscular dystrophy. People from different parts of Yugoslavia who had sick children or had muscular dystrophy themselves started attending there. This led to large groups of children and people with neuro-muscular diseases (NMD) from all over Yugoslavia descending on the General Hospital in Zenica. With the hospital's capacities overwhelmed a group of us was transferred to the Spa for Rheumatic Diseases in Fojnica near Sarajevo. There I met other people from Serbia, Macedonia, Croatia, Bosnia, various parts of Yugoslavia with neuromuscular diseases.

And as we mingled and hung out, we realised that no one knew how many people there were with NMD in Yugoslavia at all. Absolutely zilch was known! At the time we started our activities, NMDs were a completely unknown phenomenon, save for a close-knit circle of experts who treated them and families who were directly affected. At that time, having muscular dystrophy meant that you didn't have any disability-based rights, nor did we have the legally recognised status that we have today. In fact, this was the catalyst for the idea that only if we unite and

Gordana with the group of muscular dystrophy activists at the General Hospital in Zenica establish an organisation do we have a chance of achieving something. It was a shared hope of doing something for ourselves and for others, and so in November of 1966 we held an inaugural meeting and founded an association based in Fojnica. I still have a picture from that meeting, which shows a flag emblazoned with the five-pointed star hanging behind the group chairing the meeting and it reads: “Workers of the world, unite”.

From the left to the right - Dušan Jandrić, Dr. Ante Blažević, Rajko Radmilac, Gordana Rajkov and Hasan Pašović

None of us had any experience in running an association. We had no money, no office, and no typewriter – armed only with the desire to change something for the better. We worked in pyjamas and hospital rooms. With the help of people who wanted to help, we spread the news about the founding of the Association, and soon many people with NMD from all over Yugoslavia got in contact and sought advice.

Who were the founders?

The founders were: Rajko Radmilac, Olivera Jandrić, Branislav Rajić, Mirjana Gojković and I from Serbia, brothers Boris and Andrej Šuštaršič from Slovenia, Stjepan Bosak, Zvonko Livačić, Anđelka Bistrović from Croatia, Hasan Pašović, Josip Garić, Mustafa Pubović from Bosnia and Herzegovina and others. The first chairman of the Association was Boris Šuštaršič from Ljubljana, members of the Steering Committee were: Olivera Jandrić, myself and Rajko Radmilac from Belgrade, Hasan Pašović from Sarajevo and Stjepan Bosak from Zagreb and we all had a number of responsibilities. I kept a record of members. It was known as the record of correspondence with members. Then a barrage of children turned up. This led us to the realisation that it was primarily a paediatric disease. Later, a purpose-built school was erected there for all the inpatient children.

In the Spa, they helped us as much as they could, gave us copy paper and that sort of thing. We bought the stamps ourselves. As much as we could afford. Because we were skint when we founded the association, we organised a show at the Cultural Centre in Fojnica to raise some working capital. You see, Fojnica is a bit like a village, out in the sticks, and the only thing it's known for is a famous Franciscan monastery. Each of us contributed as best we could at the show. Some recited poetry, some sang. I remember that I sang the song "*Tuđinata pusta da ostane*" ("May the foreign land remain desolate")[19] with a colleague from Macedonia...

We raised some money from the tickets and then we bought a small typewriter and started writing letters to various companies and unions to help as much as they could...We duplicated those letters on a mimeograph machine that belonged to the Spa. It was a device for duplicating texts on stencils filled with special ink and on one side a piece of paper with text is inserted and on the other blank sheets of paper. You wind a handle manually and copies come out on the other side. So those letters of ours were all purple because the ink for the stamps that it usually printed was purple. I remember that the first funding we received was from the Bačka Palanka cotton factory workers' union, where most of the workers were women. They collected some money and came to the hospital to visit us and give us the money. Then the next day we opened a savings book at the post office and with that money we printed green membership cards. To this day the colours of the Association and later of the Muscular Dystrophy Association have remained green and purple. By the way, the first emblem of the Association was a black and white drawing depicting a bird on the palm of a hand flying towards the sun. It has an olive branch on one side and "*Semper spero*" - Always hope - written on the other side. Many years later, in 1976, we adopted a new emblem designed by the academy-trained painter Aleksandar Pajvančić from Belgrade. He symbolically portrayed the figure of a person in a purple wheelchair caught in a green net.

At the time when work began to establish the Association in Fojnica, the Zagreb newspaper "Arena" sent journalist Marin Zurl to report on the status of people with muscular dystrophy. This led to "Arena" launching the "All For All" campaign to raise money to complete the half-built building of the new Spa and to build a Hospital for Rheumatic and Myopathic Diseases. The hospital in Fojnica was opened on April 5, 1969 by Jovanka Broz[20]. The Dizdarević family was originally from Fojnica, a well-known family in Bosnia, several of whom were politicians, and the wife of Rešad Dizdarević, a member

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[19] Macedonian folk song about a girl who curses a foreign land for separating her from her sweetheart. (Ed. note)

[20] Jovanka Broz was the First Lady, wife of the Yugoslav president Josip Broz - Tito (Ed. note)

of the Assembly of the Socialist Republic of Bosnia and Herzegovina and a member of the Council of the Republic, helped us and arranged meetings for us with various power brokers and orchestrated that the hospital be opened by Jovanka Broz. That's how the event gained publicity and significance.

Gordana greets Jovanka Broz at the opening of the hospital in Fojnica 1969.

It was the first hospital of its kind but no one behaved like they were in hospital. We'd wait for the doctors' rounds to finish in the morning and then we'd meet in the room they gave us for the office. That was where we got together, made plans, discussed strategy and our plan of action. We spent the whole summer in Fojnica making plans and hanging out in an atmosphere of true friendship and zeal. During the year, I'd travel back to Belgrade to attend university, but we continued our work through correspondence. We could hardly wait for spring, June, to return to Fojnica. I remember in particular Olivera, Rajko, Stojan, Nikola, from Serbia, Stjepan from Croatia, Simo and Hasan from Bosnia, for their endless energy, ideas, selfless commitment, friendship, all of whom, sadly, have passed away and I miss them dearly. I'm still great friends with Boris from Slovenia, Hasan from Bosnia and Anđelka from Croatia. This period was marked by negotiations with ministries, work to amend legislation, encouraging scientific research, travel throughout Yugoslavia and Serbia to strengthen cooperation and initiate the establishment of associations at republic, regional and local level. We went about our work full of enthusiasm, rejoicing and joking with each new milestone, which made us all feel like members of one big family that functioned on the principle of "all for all". It seems to me as if that's a thing of the past.

We kept very busy. In less than two years, at the beginning of 1968, we had established a Secretariat of the Muscular Dystrophy Association of Yugoslavia in Belgrade in order to facilitate access to politicians and power brokers (there was a message written on the door beside the address which read: "opening hours for members from 08.30 - 14.30", there was no phone). A friend in Belgrade from the municipality of Zvezdara helped us secure a small premises for our Secretariat at 23 Dimitrija Tucovića Street, which to this day houses the Muscular Dystrophy Association of Serbia.

As almost nothing was known about NMDs despite them being some of the most serious children's diseases, the onset trigger for which was unknown, as diseases that are progressive and in some cases hereditary, where you could have several sick children in one family, in ‘69 we founded the Council of Experts of the Association to collect information on these diseases and their consequences. We invited the leading experts of the time. Members of the council included, for example, Dr. Nedo Zec, PhD., from Sarajevo, academic, neuropsychiatrist, founder of the Faculty of Medicine in Sarajevo, Dr. Žanka Ilić, PhD., physiatrist from Sarajevo, Dr. Živojin Zec, physiatrist, founder of the Medical College of Higher Education in Belgrade, Dr. Borivoje Radojičić, PhD., neuropsychiatrist from Belgrade, Dr. Anica Jušić, PhD., neuropsychiatrist from Zagreb, Dr. Milan Dimitrijević, PhD.,neuropsychiatrist from Ljubljana and others who had treated NMDs, to help us define the diagnosis and treatment, and how we could help. I’ll tell you one thing, we managed to organise several international forums and conferences under our own steam using the funds secured from various state institutions. One of them was the Symposium on Myopathic Diseases, held in February 1971 in Baško Polje, and we did all the event planning ourselves. That’s how I started learning about NMDs because those were expert meetings where you could learn a lot about those diseases.

When did organisations at republic level begin to emerge?

The structure of the organisation mirrored that of the state. During the first years of the Muscular Dystrophy Association of Yugoslavia, the need to establish associations in each republic became apparent because part of the relevant legislation was enacted at that level, and so at the end of November 1968 we founded the first republic organisation - the Muscular Dystrophy Association of Serbia, followed by muscular dystrophy associations in Croatia and Slovenia in 1970, and then associations in Macedonia in 1971 and in Montenegro in 1975. After that we established associations in Kosovo and Vojvodina at the provincial level.

There was scarcely any legislation governing the status of these patients. Hasan, who had graduated in law, oversaw legislation, Stjepan Bosak from Croatia, and Boris, Olivera and I oversaw negotiations. It goes without saying that neither the chairperson nor any of us received any remuneration for our work. Everything was voluntary. And we helped each other a lot. For example, Olivera and I travelled all night from Belgrade to Sarajevo in a beat-up van belonging to the Association because my colleagues from Sarajevo had an important meeting scheduled at the Executive Council of Bosnia and Herzegovina and we went to help them lobby for the changes they had been pushing for. Then we started asking for and receiving funding from the state; at the time we had a secretary - Rada[21] who did administrative work, and later we hired a social worker in the Muscular Dystrophy Association of Serbia. We

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[21] Radmila Mirilo (Ed. note)

even hired a driver because the beat-up van gave out and then we bought a colossal Russian Volga that was difficult to drive. We travelled all over Yugoslavia in that car. Well, you know, that's how experience and knowledge are gained. First, we started to put forward proposals for changes to the Healthcare Act and that provision be made for a mandatory type of protection for people with muscular dystrophy and neuro-muscular diseases, regardless of the type of insurance (labour, agricultural).

And was healthcare at that time regulated at the federal level or did each republic have its own laws?

One part of the legislation was, of course, at the federal level, but further access to rights was regulated by each Republic for itself. So there were special laws at the republic level, for example on pension and disability insurance, health insurance, social protection, so it was necessary to establish republic organisations because we could not change or do everything we needed to do at the federal level. After the founding of the republic organisations, in June 1974 we re-registered the Association as the Federation of Muscular Dystrophy Associations of Yugoslavia - SUDJ with its headquarters in Belgrade, and the republic organisations became members of the Federation and had their headquarters in the capitals of the republics. In Macedonia, for example, the chairperson was a doctor, but in Croatia, Slovenia, Bosnia, and Serbia, we ran the muscular dystrophy organisations ourselves. Through the work of the Expert Council, the experts were there to help us with suggestions and advice on what should be changed, for example: in healthcare, the right to climatotherapy, etc.

A few years after the founding of the muscular dystrophy associations, we began to organise gatherings called the Yugoslav Muscular Dystrophy Meetings, which were held annually, and which alternated between the republics. It was a particularly beneficial event because representatives from all republic organisations attended the Meetings and each meeting covered a specific topic. One year, for example, the topic was orthopaedic aids, the next year priority was transportation, and the following year something else. That's how we went about exchanging experiences and information about what legislation and services existed in which republic, where are the best laws that you can later lobby for in your republic, taking as an example laws already in force in other republics. At the same time, the Meetings were a hive of social activity and we supported each other's efforts wholeheartedly. It was a period of immense enthusiasm.

Who were the founders of the republic organisation in Serbia?

Rajko Radmilac, brothers Nikola and Petar Durković, Obrad Cicmil and myself from Belgrade, Rajko Knežević from Kraljevo, Aca Nikolić from Kragujevac and Stojan Nastić from Leskovac. There was also several associates who were not persons with disabilities, such as Dr. Malešević and Slavko Vasiljević who helped us tremendously. I probably haven't named everyone but I can remember these associates. The inaugural meeting was held in a local community office in the municipality of Zvezdara, which was heated by an old drum furnace. The group chairing the meeting included myself, Stojan Nastić and Obrad Cicmil who was a senior diplomat and ambassador to various countries, a great man, whose son had muscular dystrophy. He helped enormously with founding the European Alliance of Muscular Dystrophy Association - EAMDA.

What was the relationship like between the Muscular Dystrophy Association, later the Federation, with the Union of the Blind and Deaf and other organisations and alliances of disabled persons?

We enjoyed a good working relationship. There was a Coordination Committee of Disability Organisations at that time. I think it was headed up by someone from the Union of the Blind, and the secretary of the Committee was Mr. Bojović, a lawyer, a most enterprising man. We cooperated with on issues of general interest, such as laws, financing for organisations, etc. The Committee was around for a long time, later it changed its name slightly, but it remained informal in character, until the National Organization of Persons with Disabilities of Serbia - NOOIS was established in 2007.

Group chairing the inaugural meeting of the Muscular Dystrophy Association of Serbia, Gordana Rajkov, Obrad Cicmil and Stojan Nastić

What was the accessibility situation like?

If we start with Fojnica, the new building was accessible, the old one was not. Those of us in accommodation in the old building watched the work progress from the window and gave suggestions as to how to make it accessible, what the corridors should look like, what width the doors should be.

In our newspaper "*Miopatija i mi*" (Myopathy and Us) we published global standards that we unearthed, as well as the accessibility features incorporated in this building. We worked for a long time on removing architectural barriers, and back in 1984 we translated European accessibility standards which were published by the then Federal Institute for Standards, so for the first time in Yugoslavia, at least on paper, accessibility standards were published. Their implementation required, of course, legislative amendments. Certainly, I was keenly aware of the situation with inaccessibility because even though I graduated with a degree in mathematics, I could never work as a school teacher due to the inaccessibility of my environment and the schools themselves. When I started using the wheelchair, the situation became even more difficult.

On that note, I was faced with a lot of prejudices and, as an example, I remember that while working on having a law amended through the Muscular Dystrophy Association, I was due to attend a meeting with the deputy minister and state the case for amending the law. Of course, I prepared diligently for the meeting, arming myself with arguments and explanations. The deputy minister received me in his office, offered me coffee, and I began to tell my story and explained why an amendment to that law was important. I spoke for a long time, in what seemed to me to be a most reasonable manner and backed-up by facts, only to realise at one point that this man was listening to me but it was going in one ear and out the other, even though he was looking at me. I mean, I wasn't getting through to him. I thought I'd done something wrong and then I stopped, and when I stopped, he looked at me very surprised and asked: "Excuse me but may I enquire if you have a degree in something? You speak so eloquently that I get the impression you went to school?" I was flummoxed because he'd actually spent the entire time just marvelling at the fact that I could talk and he hadn't listened to a word of what I'd said. To this day there is still an internal joke that when I "set about" explaining something, my colleague Mimica usually asks: - Excuse me, do you have a degree in something by any chance?

How did you come into contact with foreign organisations?

Uncle Obrad Cicmil, as we called him, who was interested in exploring that avenue, made enquiries if there were similar organisations in other countries, and that set in motion the idea of establishing a European Alliance of Muscular Distrophy Associations – EAMDA[22], which was founded in October 1970. We are one of the seven founding member states of EAMDA: The Netherlands, Belgium, Denmark, England, Italy, Germany, and Yugoslavia.

Other European countries followed suit. I think the first headquarters was in London, where the EAMDA Secretariat was located. There was a woman working as a Secretary General and the president and vice-presidents were

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[22] Now renamed to European Alliance of Neuromuscular Disorders Associations (Ed.note)

elected every two years, with their terms of office lasting four years. The executive committee consisted of a president, two vice presidents and a secretary, and they communicated with each other in writing. The EAMDA general assembly was held every year, sometime in September in one of the member states, and the executive committee met once a year between two assemblies.

In our country, by that I mean in Yugoslavia, the General Assembly and the VI EAMDA Congress were held for the first time on March 4 and 5, 1976 in Belgrade. They were held under the auspices of Zora Tomič, who was then Minister of Labour and Social Affairs. We received funding for the assembly from the then Federal Ministry, to cover the costs of accommodating all those guests from different European countries in the Hotel Yugoslavia. It was at this point that I first starting using a wheelchair because I had difficulty walking and could lose my balance in an instant, and the nature of the assembly was such that you were constantly on the go, checking if all the equipment was working, greeting guests on arrival, etc., because at the time I was president of the Yugoslav association. We also hired a Slovenian agency to help us plan the event. To get around faster and with greater ease I used a manual wheelchair. I remember chancing upon the famous professor Dimitrijević, a native of Niš, who had lived and worked for many years in Houston, USA, and he said: “Heavens! Gordana, how beautiful you look in that wheelchair!” I retorted: - Professor, what’s gotten into you, are you having a laugh? What’s great about sitting in a wheelchair? And he said: - You’ve no idea how much calmer and more relaxed you look when you’re in a wheelchair. That’s when it struck me that I was constantly tense when I was walking and I was afraid that I would fall, that someone would push me, etc., and that being in the wheelchair put those fears to rest.

There were two main aspects to the congress: a scientific medical aspect and a social expert aspect. In addition to planning the overall logistics and securing funding, I sent invitations to various experts, professors from Yugoslavia and abroad as well as doctors with various specialist backgrounds in order to raise awareness and increase professional knowledge about the existence of these diseases, their diagnosis, prevention, treatment options, etc. There were about a hundred attendees, representatives from all EAMDA member states and from Yugoslavia. I still remember two events from that forum, which illustrated the cultural differences between us and some western countries. My task, as forum organiser, was to chaperone the foreign guests after each day of the forum. So I’d sit down to dinner at a restaurant that served traditional Serbian cuisine, where there’d be some folk music, and one time a gentleman from the Danish association who was not a person with a disability asked me: - Would you care to dance? I thought he was teasing me, and I said in complete astonishment: - Beg your pardon? And added sarcastically: - If you haven’t noticed, I use a wheelchair. He replied: - You know what, don’t look for reasons not to, if you don't like me by all means say so but don't make up reasons not to dance. Of course, I didn't dance after all, I'd have been mortified to take to the podium to dance in a wheelchair: that's not who I am. But that was the difference in culture. It's commonplace nowadays. That year, another guest from Denmark, Evald Krog vice president of EAMDA who had severe muscular dystrophy from birth and was completely immobile had prepared a presentation about sexuality among people with muscular dystrophy. Imagine that, forty years ago!!! Unfortunately, he got pneumonia and had to stay in his room to receive injections. His paper was read by his associate Bruno Manson, a stern lawyer who did not have a disability. And the paper read something like this: I have sex with my wife three times every other night, she throws my leg over I don't know what and I move my left arm, then she moves her right leg...right down to the nitty-gritty. You should have seen it - an auditorium full of professors and doctors, while standing behind the rostrum is this man detailing Evald's sex acrobatics. The interpreter came racing out of the booth in a panic and said: - Gordana, what's this all about? What do we do? And nowadays they are engineering sexual assistants on Facebook.

And life unfolds elsewhere.

Well my dears, it was all already...

But it was the first time that someone had dared broach the subject, and the Yugoslav doctors in attendance, in fact everyone, was horrified and shell-shocked. What's this all about? An expert forum to review medical research and papers examining how muscle cells develop, chromosomes, symptoms and all the rest, and now here's this happy chappy harping on about sex positions! So, aside from it being the first time I started to use a wheelchair occasionally, that first EAMDA that we organised in Belgrade really left an indelible impression on me.

Who helped you in your work?

While I was more physically independent, I was mostly able to do all the work on my own. However, as our efforts gained momentum, those of us at the Muscular Dystrophy Association published a vacancy announcement for a technical secretary. Mimica Živadinović, who had graduated in sociology but could not find a job in the profession applied for the vacancy. But it was clear from her CV that she was a diligent person because she had held various posts, and she lived with her parents in New Belgrade. We interviewed all the candidates on October 23, 1987, and when we finished the interview with Mimica, she produced a box and said: - Here, I brought you mini vanilla cakes as a treat because it's my birthday. We glanced at her CV and lo and behold it was her birthday. Almost thirty years have passed since then. That's how we hired Mimica to work at the Association.

At that time, the offices of the Muscular Dystrophy Association of Yugoslavia were in Dedinje[23] because we swapped them for the previous office near the Stari Đeram farmers' market. It remains the headquarters of the Center for Independent Living Serbia. Mimica worked in the office as the technical secretary, discharged administrative and financial duties, maintained communication with members of the Alliance and members of the European organisation, helped with publishing activities, posted various correspondence because of course there were no emails then, and she also often accompanied me when I travelled to international and other meetings. She was practically my first "personal assistant", because that concept hadn't been heard of at that time.

Two years after she started work at the Alliance I fell and broke my leg. They put a huge cast on me. I lived alone and couldn't get by on my own in the house. Then Mimica suggested: - "If you want, I'll come and stay with you?" And so, she would go to work in the morning while the nurse was there, and when she came from work she was with me in the afternoon and overnight. I couldn't move an inch with that cast. By the time they removed the cast and the rehab was over, Mimica had already entered the "world of people with disabilities", where, as a sociologist, she had no problem finding her feet and met some great, witty people and fell in love with the work. She still says to this day: - I could only work for "dystrophics". Then we agreed that she would stay and continue to live with me. That's how the two of us came to live together and we lived in the same apartment for about ten years, and for about a year after Mimica's son, Luka, was born.

What was your remit at the European Alliance of Neuromuscular Disorders Associations?

I was a delegate of the Muscular Dystrophy Association of Yugoslavia at the EAMDA for a long time and I was its vice president for twelve years. My specific remit was cooperation with Eastern European countries that at the time did not have such organisations. I was the president of the European organisation for two years.

When the war broke out in Bosnia our colleagues found themselves in a precarious situation. Hasan and his wife Rada, both wheelchair users, lived in Sarajevo in a building on the third floor, which was shelled frequently, and they spent three months in effect in the bathroom of the apartment because it was in the middle of the apartment and offered the most protection. They couldn't even get food and those of us in Belgrade attempted to send parcels through the religious organisation ADRA. With no way of finding out if a parcel had arrived or not, we got colleagues from the Belgrade Association who were amateur radio operators to let them know that we had sent something, and the

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[23] A suburb of Belgrade. (Ed. note)

operators in Belgrade relayed this message to amateur radio operators in Macedonia who could get through to people in Sarajevo. After a month, we got word that they'd received the parcel and how much it meant to them.

In 1991, in cooperation and constant communication with the muscular dystrophy associations of Denmark and Germany, we considered the possibility of evacuating a group of people with muscular dystrophy from Bosnia and Herzegovina, but that idea failed to gather traction and was put on the back burner.

One of my last EAMDA Annual Assemblies was in Sweden in 1992. My colleague Mimica and I travelled to the Assembly by employing some trickery because the Association practically didn't exist anymore, nor did we have any money. We wrote to JAT (Yugoslav Airlines) to give us discounted airline tickets and we got a sizeable discount. We financed the tickets ourselves and went to the annual assembly because it was important for us to talk about the situation in Yugoslavia, which had disintegrated for all intents and purposes, and to seek help for our colleagues, friends from Sarajevo. We were quite despondent on that trip to the forum in Sweden. I couldn't care less if someone is a Serb, a Croat or a Muslim. These were people we'd been working with for years and we were upset by the situation our friends in Sarajevo found themselves in, among whom, of course, were people of all three religions and nationalities. During the proceedings I spoke about the situation in Bosnia and asked if there was a possibility of EAMDA assisting with the evacuation of people from Sarajevo or providing assistance of any kind. Alas, no resolution was passed. That evening, at the gala dinner, someone came up with the idea that each of the attendees would sing a song from their country. Mimica and I had kept quiet when at some point the hosts remembered that we were there and said: - Wonderful, now a song from Serbia! Had they lost the plot, a song from Serbia? Serbia was front page news, in all the newspapers, pandemonium, pilloried, "carrying out a massacre" in Sarajevo, and now all that was needed was for us to sing a song from Serbia in Sweden, as if nothing was happening. We declined, but they insisted, void of any tact or understanding. Still stunned, we again said that we'd rather not, but it was bordering on the ridiculous, we couldn't sit around there for two hours, those people had known us for years, we'd been working with them for years. I've no idea how we thought of it, in any case, in the end we said that we didn't want to sing but given their insistence we said we'd sing a song from Bosnia in support of our friends living through turbulent times in Sarajevo. We both started singing the song, I remember well, "*Grana od bora*" (*Pine Branch*), which originates from Bosnia and tells the tale of a Serbian girl, and which was often sung at our meetings throughout Yugoslavia. We finished the first stanza and burst into floods of tears. We were crying, the people who were sitting with us at the table were crying, and sitting her now recalling all this, I could cry again, it was so upsetting for us then. Our thoughts were with all those friends of ours...And our crying bore fruit because then the delegations from Ireland and Germany decided to help us, because they also cried with us. The European Alliance of Neuromuscular Disorders Associations collected money for the evacuation and plane tickets from various EAMDA members, and Gregor Schwartz president of the German Muscular Dystrophy Association, who also suffered from muscular dystrophy, arranged for the group to be admitted to Germany. We managed to evacuate a group of fifteen people from Sarajevo with their companions, family members. From Sarajevo, they travelled by bus to Dubrovnik and from there by plane to Germany. After that, Mimica and I participated in two more annual EAMDA assemblies, in 1993 in Aarhus, Denmark, and in 1994 in Glasgow, Scotland. The Association was essentially no more at that time, and Mimica and I raised funds to attend those assemblies in order to maintain continuity, because the republic muscular dystrophy organisations that had split off had not yet become independent members of EAMDA. Those were the last European annual assemblies that I attended with Mimica. A few years ago, I attended the EAMDA assemblies in Ljubljana and Belgrade, but it’s not “the same” organisation it once was.

When did you begin publishing your paper and who edited it?

We started publishing our newspaper “*Miopatija i mi*” (*Myopathy and Us*) back in 1968, two years after the founding of the first muscular dystrophy association in the region. I have three volumes of hardcover issues of the newspaper “*Miopatija i mi*”, which published news of everything happening in the Association, what was being done in other countries, the latest research and treatments from around the world...When associations began to be spring up in the republics we began carrying news about what was happening in each republic. As for the language: if the articles came from Slovenia, they were published in Slovenian, from Macedonia in Macedonian.

Olivera Jandrić and Gordana Rajkov at the NMD Symposium in Baško polje in 1971

“*Miopatija*” was first edited by Olivera. She read a lot and had her own vision of what the newspaper should look like. She took photos, took pictures of different people, children in wheelchairs and so on. When Olivera passed away, “*Miopatija*” was edited for several years by Rade Radivojevć, then Rajko Knežević from Kraljevo, and following Rajko’s passing, Predrag Cicmil from

Belgrade. After his departure, I edited “*Miopatija*” from 1986 to 1988. And then came the war, everything fell apart and the newspaper stopped publishing after twenty-two years in print. It’s long since been discontinued, but it’s a pity it wasn’t kept alive, because it was a fantastic newspaper. As part of “*Miopatija*”, we also published a section that we called the *Zeleni dodatak* (Green Supplement) because it was printed on green paper and was a thematic supplement to the newspaper. It covered different medical topics, news about different types of neuromuscular diseases, etc., and the authors were renowned experts. Later editions of “*Miopatija*” always included those green supplements that ran professional articles, and which were a revelation for neurologists who worked in hospitals, because they didn’t know anything about it.

Looking back, how do you regard your work in muscular dystrophy organisations?

When I look back on what I, together with my friends and associates, achieved up to 1991 during the twenty-four-year existence of the muscular dystrophy organisation, the list is impressive.

From being a complete unknown, NMDs have a high level of visibility, both among experts and in the legislature. We succeeded in putting the problems of patients with neuromuscular diseases on the map and educating the relevant professional institutions and the public about them. We advanced scientific research work in this field and worked on providing practical assistance where we could. At the time of the founding of the first muscular dystrophy organisation, there was no institution that dealt with these issues. We managed to establish two specialised institutions for diagnosis and rehabilitation of these diseases, in Fojnica and Novi Pazar, while at the university clinics in Belgrade, Zagreb and Ljubljana there are centres dealing with this issue. We also organised several professional forums, such as the first professional forum in 1971 in Baško polje and the Third Yugoslav Symposium on Neuromuscular Diseases in Ljubljana in 1986. This work was done in close cooperation with the Council of Experts of the Muscular Dystrophy Association of Yugoslavia, which was founded in 1969. The principle that underpinned the cooperation with the Council of Experts was that people with muscular dystrophy must be part of a multidisciplinary team that discusses these issues.

At the time of the organisation’s establishment, basic healthcare was practically non-existent for those who had neuromuscular diseases due to the absence of legislative recognition of these diseases. Therefore, we worked tirelessly to improve healthcare and rehabilitation, and the result was improved legal protection, because there were almost no healthcare regulations that catered for the rights of people with muscular dystrophy. We also fought for neuromuscular diseases to be covered by mandatory types of healthcare. Many people don’t know that thirty years ago we managed to secure the right to carer’s allowance. The right to import orthopaedic aids that are not produced in the country, duty-free, was also secured.

We invested a lot of effort in revising or enacting new regulations in the field of education, bearing in mind that many young people, due to the progression of the disease, dropped out of school and consequently were left without prospects for employment later. In the field of employment, a reduced service retirement benefit was introduced for people with neuromuscular diseases, and a self-employment scheme was launched by organising small photocopy shops attached to the associations, which also allowed them to assert their ability to work. Tax and social protection regulations were amended, and transport and utility payment benefits were introduced.

A lot of activities were aimed at raising awareness about accessibility and architectural barriers, and Slovenia and Croatia enacted laws related to ensuring accessibility. The legislative work was coordinated by the Council for Monitoring and Implementing Legislation, which was led by our friend Stjepan Bosak from Zagreb.

I’ve already talked about the lack of information on these issues, and our newspaper “*Miopatija i mi*”, which I’ve already mentioned, was the source of a large amount of information for experts, patients, their families and scientific research. In addition to publishing magazines, we worked on translating other professional literature and publications, which we published ourselves.

I’ve already mentioned that we enjoyed fruitful international cooperation both through the EAMDA, and through the exchange of experiences in scientific research, publications, and information from other countries. Of course, we were continuously working on the development of our organisation through the establishment of republic, provincial and local muscular dystrophy associations, of which there were fifty-six throughout Yugoslavia at the end of 1990.

However, the greatest achievement was the breaking down of prejudices and general social attitudes about people with muscular dystrophy and gaining recognition for ourselves as capable and equal members of society who ought not to be viewed by others as objects, rather as people and to be free to make our own choices.

Of course, I’d been active in the organisation for all twenty-five years, I was one of its founders, holding various positions: vice president, president, secretary general of the Presidency of the Muscular Dystrophy Association of Yugoslavia at different periods of the organisation’s history. And I was, of course, among the founders of the republic association in Serbia. As I already mentioned, I actively participated in the work of EAMDA, I was the vice president for eleven years and the president of the organisation for two years, as the first woman to take charge of this European organisation.

I was involved in shaping the strategy and planning the activities of the organisation, amending legislation, reaching out to scientists, experts, decision makers in various federal and republic ministries. As I'm not one to give up easily, if I couldn't get hold of a person we needed in writing or by phone, I'd set off early in the morning, before office hours, to whatever institution that person worked at and wait in front of their office until they arrived...Of course, I always knew to be polite, kind, but confident, never despondent or telling sob-stories. I was never turned away and always managed to grab at least five to ten minutes of someone's time to explain what it was I was after.

As most of the federal authorities were located in New Belgrade in buildings that were commonly called SIV II and SIV III[24], I had a constant struggle with the mountains of entrance steps. I always had to ask the people around me to ferry me in and out of the building with the wheelchair. It was a very embarrassing experience, but what can you do - if you want to get something done that's the only way.

What I am very proud of is the fact that society at that time recognised the value of the work our organisation was doing and the people working in it, which led to activists of the Muscular Dystrophy Association of Yugoslavia receiving very high state commendations on two occasions. The first commendation marked the tenth anniversary of the organisation when five of us - Boris Šuštaršič (Slovenia), Hasan Pašović (Bosnia and Herzegovina), Stjepan Bosak (Croatia), Aranđel Radmilac, and I (Serbia), received the Order of Labour with Silver Wreath, which was signed by the President of the Republic, Josip Broz - Tito, and the commendation was presented in 1976 in Fojnica by comrade Momir Kapor, a member of the Presidency of Bosnia and Herzegovina. Of the five decorated, I was the only woman.

The Order of Labour with Silver Wreath Award winners from left to right: Aranđel Radmilac, Gordana Rajkov, Boris Šuštaršič, Hasan Pašović and Stjepan Bosak

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[24] Buildings of the Federal Executive Council, the federal government - SIV, which were situated at various locations. (Ed. note)

To mark the twentieth anniversary of the organisation, Hasan Pašović, Stjepan Bosak, Boris Šuštaršič and I received the Order for Services to the Nation with Silver Rays for Special Merits and Achievements of Importance for the Socialist Development of the Country, while the Order of Labour was awarded to our colleagues Simo Petković, Rajko Knežević and Ferenc Lukač. And again, of the seven decorated people with muscular dystrophy, I was the only woman. As far as I know, that was the first time that persons with disabilities from a non-governmental organisation, veterans' organisations aside, had received very high state recognitions for the work and development of an organisation for persons with disabilities. The award was presented by Zora Tomič, a member of the Presidency of the Socialist Federal Republic of Yugoslavia, who said in her welcome speech: - Offices, tables and typewriters do not make an organisation, an organisation is made by the people who congregate there and fight for the benefit of all.

Momir Kapor, a member of the Presidency of Bosnia and Herzegovina, presents the Order of Labour to Gordana Rajkov, in 1976 in Fojnica

Which of your close associates at the time is still active?

Now only Boris, Hasan[25], Anđelka, and I are still alive. Boris still heads up the Muscular Dystrophy Association of Slovenia. Anđelka does her best to be involved in the local organisation in Virovitica, and Hasan and his wife now live in Germany. He has far better healthcare there than here and enjoys universal accessibility. He visits Sarajevo for two months in the summer and then returns to Germany.

Let's turn our attention to your personal life again. What was the period like after your brother returned from the army?

My brother went to work in Germany not long after returning from the army. Of course, he occasionally came to visit for a couple of days, but he lived in Germany. So, practically, I've been living alone since I was twenty-three.

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[25] Between the time when the first edition of the book was published (2017), and the time of translating this book to English (2020), both Boris (1946 – 2019) and Hasan (1945- 2020) have passed away. (Ed.note)

Up until the age of about thirty-two or thirty-three, I could walk and do routine things on my own, get up, go to the toilet and all the rest. The only thing I needed was transport to the Association or whenever we went to meetings and negotiations. We used a taxi, and later we procured our own vehicle, but it was always complicated, because the wheelchairs had to be folded and unfolded every time I got in and out of the car. I avoided being in the wheelchair around the house, I only used the wheelchair when I went outside. Of course, given that the dystrophy kept progressing at a rate of its own, I later had to use a wheelchair to go everywhere, especially after one incident in the bathroom when I was home alone and couldn't get from one point to another. Then I realised I had to use the wheelchair once and for all. By then, I had already graduated from university and since I couldn't work in a school due to various architectural barriers, I started giving maths grinds (private lessons) at home. It's one of the jobs I really loved doing the most. The only downside to it was that I stayed in the house, ventured out less and didn't have enough contact with others. I used to give five or six grinds a day, working almost full-time hours and more. I mostly tutored students from comprehensive school, because my friend Žiža, who also had a degree in maths, worked at the Tenth Belgrade Gymnasium and she referred students to me who had difficulties with maths. They were second-third-fourth grade comprehensive students, grown-up boys and girls, which made me a little older than them and we got along well. From talking to them I knew what was in fashion, what was hip, the language they used and the like. You stay young when you are constantly in the company of young people. I loved those children dearly, and to this day, all these years later,

I remember the excuses they came up with. One was constantly late but he always somehow found another excuse: his granny sent him out to get medicine, the bus didn't arrive, he had to go and do God knows what, but he was religiously late. Another would come to class carrying a newspaper and say: - Here. I've brought you the newspaper so you can read a little. Claiming that he knew it all anyway, he thought I may as well look through the newspaper while he does his homework. I also remember a girl who once had to do some very simple arithmetic, which I knew she could do, but she always got the wrong answer. When she'd finish, I'd say: - Well if that's the answer, I'm Pope Pius XII. She'd put out her hand and say: - Nice to meet you, I'm Ksenija! Those children were a riot. And there was one guy, very serious, I worked with him on descriptive geometry. In descriptive geometry, there is a procedure for projecting a figure or body onto a given plane, and in order to obtain the true size of that figure, the expression "topple" a straight or other figure into a certain plane was used. We had to "topple" the skew marked with C and K, which was a very simple procedure, which he'd done several times. At some point "his brain would freeze" and he couldn't do it. When he'd finish, I'd say: - Well, we've done that plenty of times, how do we "topple" CK[26]?" He'd look at me sternly and say: - Professor, with difficulty!

I took great pleasure in working with the students. One guy, his name was Janoš, injured his right hand and couldn't write. I said: - All right, when you're better give me a call. - No, no, no, he said, I'll come to class, I'll try with my left hand. For the love of God, his left hand! What was he on about, we'll be left with pages full of squiggles. - All right, I'll write, and you dictate. This went on for ages, but I always had endless patience. And when he'd get bored, he'd say: - "Professor, you know what, is there any chance we can talk about something other than maths?" I'd say: - Janoš, no, you're here for grinds, that's first and foremost. When the school year ends, we'll do a deal and you can come over and we'll talk about whatever you want. And so the school year came to an end, he passed all his exams and called one day and said: - Do you remember you promised that I'd could come for a grind of sorts and that we'd talk about anything and everything? He turned up alright and we spent time talking about various things that had nothing to do with school. Long story short, the children were wonderful, and when they got a good grade in school, I bought them chocolates as a reward for mastering it and they always sent me postcards from the seaside.

To this day I meet people I taught, and they ask me if I remember them. Unfortunately, I no longer remember all their faces and names after more than forty years. I recently met a lady who approached me and laughed. I look around to see who is behind me that she knows. The woman came up to me and said: - Hello, how are you? But I didn't recognise the woman and I asked her: - Excuse me, but how do we know each other? She replied: - You taught me while I was in comprehensive school. I remember you; you were the best maths teacher ever, nobody was ever able to explain things to me like you could. I see you now and then on television and, proud as punch, I tell my children: That's my maths teacher! Those encounters leave me with a nice feeling and they always brighten up my day.

Of course, apart from those maths grinds, I was also involved in the Muscular Dystrophy Association. I saved the money from the grinds mostly so I could travel around.

I had a lot of girlfriends and friends. Nowadays I have three or so girlfriends that I still hang out with even decades later.

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[26] CK was an abbreviation for the Central Committee of the Communist Party of Yugoslavia, which was the executive in the Socialist Federal Republic of Yugoslavia. To "topple CK" may read as "overthrow the Central Committee" (Ed. note)

How did you meet them: at uni, in comprehensive school or after?

I meet them in various ways, mostly through other people. I had a relationship with a guy who had a master's degree in history, and then through him I met his friend Braca, and then his girlfriend, Vesna. Through her, I met other friends Ljilja and Lola, and so on and so on. Even today, I'm in regular contact and hang out with them, even though they each have their own business careers, children and their own lives. Lola was the director of the Hydrometeorological Institute of Serbia for some time, and Ljilja works in the Civil Aviation Directorate, both are meteorologists by profession. Vesna works as curator and head of department at the Museum of Yugoslavia. And that's how I met Desa[27], because Desa worked with Vesna at the Museum. When I moved in 2000 to the apartment I live in now, I was looking for someone who could live with me, Vesna said: - I'll tell you what, I'll ask a colleague who commutes from Lazarevac every day, so it might work for her to move to Belgrade. That's how the circles of acquaintance and friendship expanded.

Did you avail of any of the social protection services available at the time?

I used a home care service and later a home help service. When I started using this service I was still walking and this service was organised in a completely different way. As I lived alone and I had mobility problems and couldn't go shopping, I received home care four hours a day, and at one stage it went up to six hours. The "caregiver"[28], who came in the morning, would stop by the market on the way, buy groceries, prepare lunch, then the next day we'd plan to iron clothes, tidy the apartment and the like. We usually made a weekly plan and that was enough for me to do all the work, because she usually came in the morning, so she helped me with my personal hygiene and then whatever I'd need during the day. It worked well for many years.

Later, this institution was restructured, and the content of the service was changed, so that today it's half an hour of home care, which is reserved for "medical issues". A so-called senior care housekeeping service was also introduced, so I had both services for a while. But it was a complicated set-up because their duties were varied and strictly defined. The person who came as part of the home care and treatment service helped me with personal hygiene and maybe made me coffee in the morning and "transferred me" to the wheelchair, but she couldn't wash up that cup because that needed to be done by the senior care housekeeper, while the person who came as the senior care housekeeper couldn't under any circumstances help you go to the toilet. That's why I'm a fervent believer that the system must designed in a way that the service "chaperones" the person, and for a person and his/her needs to be

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[27] Desanka Simić, who lives with Gordana today as well (Ed. note)

[28] The title used at the time. (Ed. note)

divided into different services, which are very difficult to coordinate, and both services serve the same purpose of providing basic living needs. Although I didn’t know about the concept of personal assistants at the time, I felt that the organisation needed to take a different course and adapt to the individual needs of each person.

Before that, I’d just like to ask you what year did you move out of the house where you were born, to your previous apartment, and then to this one?

I moved into this apartment in September 2000. Before that, I lived in Maksima Gorkog Street. We moved there because the house where I was born had been demolished. When mam died, we had already moved into that apartment. And dad died when we were in that first house, and at the time those small family houses were demolished and joint-stock companies were building large residential buildings in their place.

And did you own the apartment or was it also rented?

No, we had a lease, and the owner was a company. Well, then a law was passed whereby you could buy apartments that were under lease, and that’s how I bought that apartment.

You bought it using the money you earned from grinds?

Yes. I never received a dinar while working in the Association. Never. Save for travel expenses I received if I travelled somewhere in an official capacity. And possibly accommodation expenses. But for the work I did, I never got paid. Of course, as I worked for the British agency OXFAM for seven years, I was able to save money from that income, which I later used to buy the apartment. I sold the old apartment in 2000 because it was on the third floor and the elevator was constantly breaking down, and that was a big problem for coming and going from the apartment.

So, I ended up selling it and buying this one which is on the ground floor to make it easier on myself. For me, who had to do all this alone, it was a very difficult and complicated endeavour. Agencies were just interested in how they could sell your apartment and they had no interest in spending any great deal of time looking for something that suited you. It was very difficult for me to get around using a wheelchair, without transportation, to visit different parts of the city and look at apartments that I usually couldn’t access, which didn’t meet my requirements or were out of my price range, and without anyone to help me. Anyone who has moved home like that knows what an arduous task it is.

In the end, I enlisted the help of a friend to keep an eye on the advertisements and scope out apartments that seemed acceptable, and then I’d go to view only the apartments that he felt were viable options. I think he looked at over twenty apartments, I looked at about eight to ten before I found this apartment, which was also not accessible, but it was the easiest for adapting and for installing external ramps, something which my neighbours did their living best to prevent. Eventually they simmered down. Naturally, I paid for the adaptation myself, not to mention the packing and moving...For the physical jobs, of course, I had to ask a friend or pay someone; however, all the worries about money, organisation and the decision-making were on me. It was one of the many great challenges in my life that I had to overcome on my own!

PART III
BIRTH OF THE INDEPENDENT LIVING MOVEMENT IN SERBIA

What happened between 1991, when the wars and sanctions began, and your departure for Ireland?

I continued to give grinds. When the war broke out, the state system began to fall apart. The organisation also fell apart. Other than giving grinds, I also worked in the Association as much as I could, but by that stage there wasn't much for me to do in the Muscular Dystrophy Association of Yugoslavia because there wasn't much more that could be done. I hadn't had much involvement in the Muscular Dystrophy Association of Serbia because my work took place mainly at the level of Yugoslavia and at the European level. Nevertheless, I attended the 1992 EAMDA Executive Committee meeting in London as a vice president, and Ms. Judy Windle[29] from Ireland, who was the secretary general of EAMDA at the time, invited me and Mimica to travel to Dublin from London for a week or two after the Executive Committee meeting to "get away" from the war situation, and to assist Muscular Dystrophy Ireland in organising a seminar on the social inclusion of people with muscular dystrophy in Ireland. After the meeting in London, we went to Dublin where we were put up in a hotel for two days.

At that time, the Dublin Centre for Independent Living had just been established and they had recently launched a personal assistant scheme through the EU TEMPUS programme.

Before founding the Dublin Centre for Independent Living, they put together a small team that went to England to see how the personal assistance (PA) system worked there and to share experience. On the back of that fact-finding mission, they cherry-picked parts of the PA service model, and later we at the Center in Serbia applied the Irish model and adjusted it to the conditions in Serbia. They started out with about fifteen people who were assigned personal assistants, who then turned into activists who were willing to fight for this service as a result of having experienced a different quality of life as it gave them a new lease of life and they knew what they were fighting for. The story always went: you can't fight for an accessible bus if you've never travelled in an accessible bus. And you can't push for personal assistance if you don't know what that means and if you haven't had a personal assistant or felt what it's like to have one at some point in your life...

Rather than have us in a hotel during our time in Dublin, Mimica and I were given the option of moving into an apartment that they had rented for a girl suffering from muscular dystrophy who had moved to that apartment fifteen days before as one of the beneficiaries of the newly launched personal

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[29] Judy Windle, Director of Muscular Distrophy Ireland at that time (Ed.note)

assistant service. Having never lived alone before she wasn’t accustomed to making decisions on her own, and already forty-three years old, she was completely at a loss as to how she would function on her own and coordinate with her personal assistant because she had seven sisters and they “moved” her from one sister to another to take turns caring for her. So, they gave us the option of staying with her and to help her cope with her new living arrangement. Her name was Florence Dougal[30] (we all affectionately called her Flo) and her only schooling was at the primary school at the hospital where she spent part of her life.

After the seminar, the Muscular Dystrophy Association of Ireland (MDI) asked me to stay in Dublin and work for the Dublin Centre for Independent Living, and to continue providing support to Flo. Mimica had to return to Belgrade because at that time she was already employed as a proofreader at the “Glas” printing house in Belgrade.

What was the connection between the MDI and the Dublin Centre for Independent Living?

Gordana with Flo and Martin in Dublin, 1994

The centre was founded mainly by people with muscular dystrophy and was the brainchild of Martin Naughton[31], who brought together Florence,

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[30] Florence Dougal (1949-2016), one of the founders of the Dublin Centre for Independent Living and very active leader (Ed.note)

[31] Martin Naughton (1954-2016), one of the key leaders of the Irish and European independent living movement (ILM). Further information at: http://www.dublincil.org/history.asp (Ed.note)

Hubert McCormack[32], Ursula Hegarty, all of whom had muscular dystrophy and all of whom were also members of MDI. Also, there were, Michael McCabe[33], Dermot Walsh, Peter Moore, who all had cerebral palsy consequences. Some of the main leaders, like Martin, spent their childhood and youth in residential care institutions, which was commonplace in Ireland. Along with me, there was a girl in Dublin who had muscular dystrophy (Jana) from America. She was involved in PR because those running the Centre decided to invite disability movement campaigners from other countries to motivate their members who knew nothing about independent living, so that they could share their experience with other people with disabilities. I went there in February 1992, and instead of two weeks I stayed almost until the end of June. I found it extremely difficult to adjust because I'd never been so far from home alone before. Mimica returned to Dublin in May and stayed with me until the end of June when we returned home together.

I returned to Dublin again in September of the same year because Martin asked me to continue working for the Dublin Centre. I accepted, provided there was no time limit, that is, that I alone would decide when I'd return home. So, I spent four years there working on various projects, returning to Belgrade every summer for two or three months to bask in the warmth and love of my friends at home, returning to Dublin again in the autumn.

I was drafted in to teach the first disability studies course at Maynooth University in Dublin, and that's where I actually started reading Colin Barnes[34] and other theorists who have written about the independent living of people with disabilities. At the same time, I was offered the job of managing a programme that the Centre had just launched called *Operation Get out*, with the idea being to find eight or nine people in residential care and to "move" them out of the institutions and into private accommodation, to provide them with personal assistants so they could try to live independently. In fact, the entire project involved research also, as my job and that of my colleague was to monitor and document the project's progress, what the main problems were, what aspects required attention. That's how the project got the name *Operation Get out* because it facilitated the transition from residential care to living independently. I worked on that project with an associate named Gráinne who used to work at MDI, because in Ireland the rule was that if you want to enrol in university (and she wanted to study sociology), you first had to work for a year in an institution or an association that dealt with your intended field of study. I'm still good friends with Gráinne[35] and we're in regular contact and meet occasionally.

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[32] Hubert McCormack, member of MDI and active leader in CIL Dublin (Ed.note)

[33] Michael McCabe, president of the Centre for Independent Living Ireland

[34] Sociologist, founder of the Disability Studies course at the University of Leeds in England (Ed.note)

[35] Gráinne McGettrick, researcher at MDI and a stalwart of CIL Dublin (Ed.note)

The question and the problem was, of course, how to teach people to live independently after so many years of living in an institution. We visited various residential care facilities and interviewed people who had expressed an interest in the programme. I remember a girl named Mairéad who had cerebral palsy and couldn't speak at all. She had a very primitive device, like a keyboard, which she used to type what she wanted to say, and which had a small screen that displayed the typed words. She held that device in her lap in front of her (she used a wheelchair) and that's how she communicated with people. I remember asking her at the interview: - Ok, why would you want to leave this place, it seems comfortable and nice! She gave a two-worded response: *comfortable prison*. And that was a textbook definition of an institution in just two words. Because she communicated via that keyboard, she always gave as short and concise an answer as possible, so that she wouldn't have to type a lot. But she was fantastic, she took the train to the library at Trinity College every day, and when she couldn't get on the train, she'd ask those around her to give her a hand. She was one of those people who entered the programme and who today lives independently with the support of personal assistants. At first it was difficult for her, and for me because I couldn't communicate with her on the phone and find out if everything was okay. She came one day and complained that her assistants were communicating with each other and handing her over "as a duty" to each other, explaining what she might need, without her having any involvement in that communication. They also helped themselves to her food and other things without asking. I told her to write a "code of conduct" for personal assistants and hang it in a visible place on the wall. I'll never forget her smile when she got her friend to ask me over and proudly showed me the "code of conduct" hanging on the wall. That put an end to those troubles.

I also remember brothers Michael and Thomas who were in that programme as well. Both had Duchenne muscular dystrophy (which is very progressive), one was eighteen and the other twenty-one years old. They'd spent their entire lives in the hospital, where their parents left them when they were little and never visited them again. When they joined the programme, we rented them an apartment, relatively close to where Flo and I lived, and they were assigned personal assistants. I took great care of them because they'd never lived independently and the children hadn't a clue about everyday life and what it entailed. I called them every day to check if they'd bought bread, milk, what food they had, if they'd paid the electricity bill, etc. The apartment was lacking some of the most basic items and equipment, such as kitchen items (plates, cutlery and cooking utensils), an iron, sheets, bedding, and so on. I suggested that we all go shopping together and that they choose what they like. We entered the store and I asked: - What bedding do you like? They said: - Which one do you want. I insisted: - No, it's not about the one I want, which one do you like? Of course, I hadn't attended any training prior to that, but went instead with my instinct and experience of independent living. Well, I'd spent many years living alone.

Before the two boys moved from the institution to the rented apartment, a telephone had to be installed. We waited ten days! Still no sign of the telephone being installed. In the end, I rang the telephone company and said: - Let me tell you something, these lads are moving in in three days and a senior Government official will be there to oversee it, so it wouldn't really do if there was no phone installed. The telephone company called the landlady and said that they'd be over right away because someone from the Government was coming to the apartment to see how the programme was going. So the landlady, all in a fluster, rang Martin and said: - Why didn't someone tell me that this politician is coming, what am I going to do now? Martin was also confused, he rang me and asked what this woman was talking about and who was coming to visit without him knowing? I said: - Well, no one is coming, but I had to think of a way of getting them to finish the job as soon as possible. A phone was installed two days later. They told me I carried on as if I were from Ireland because that's the kind of thing they would think up of. They didn't believe that someone from another country could have that mindset.

The younger brother was in poor health. He was scared witless in the non-hospital environment, he was hyperventilating and constantly upset as he didn't know if he'd receive the same medical care as before because he was accustomed to having a doctor or nurse nearby. However, I got the impression that the older brother would have set out for Mars if he had the chance, and he persuaded the younger brother to leave the hospital and start living independently. After about a month, the younger brother told me that he'd like to return to the institution but was afraid that we'd be angry. Not only was I not angry, but on the contrary, I was delighted because it was the first independent decision he'd made in his entire life. He'd always done what his brother wanted. The whole idea of the project was that if you felt that you wanted to return to the institution, it's okay to do so. He returned to the institution, and his brother continued to live independently with the support of personal assistants.

Left to right: Olga from Spain, Grainne and Gordana, Dublin 1993.

So, Gráinne and I designed a special programme for making the transition from residential care to independent living, which covered all the situations and challenges that might await. The goal of that project, which was in a way a precursor to the process of deinstitutionalisation, was to draft a Guide for transitioning from residential care to independent living, which, unfortunately, never saw the light of day. I believe that a project like that and a Guide would be more than welcome in Serbia, especially in the process of deinstitutionalisation, when attempting to move people away from institutions and returning them to live in their natural environment with appropriate support services in the local community.

There was a need to organise training about the philosophy of independent living, including the basic principles of choice, independent decision-making, control, etc., as well as functioning with the support of personal assistants. Mimica also completed a personal assistant training course in Ireland. Then I had an epiphany! Everything that had been discussed was what I'd been doing for years, only I didn't realise that it was called the philosophy and principles of independent living. So, working on that project also allowed me to put my personal experience into a theoretical framework. When the financing for that project ran out, there were no more funds for the continuation of the personal assistance programme, so it should have for all intents and purposes been abolished. Activists and former beneficiaries requested an audience with An Taoiseach (Prime Minister of Ireland), and since no one wanted to receive the delegation, we decided to protest. We spent two days and all night outside Dáil Éireann (Irish Parliament). We slept there on the street, someone brought some sleeping bags, and people who lived close by or were associates of the Centre brought us tea, soup, and sometimes whiskey to

Gordana with Flo and Martin at a protest outside Dáil Éireann in 1994 keep us warm because it was Baltic with the odd shower of rain. However, we were resolute and had no intention of leaving there until the minister in charge received the delegation from the Centre. Having been granted an audience at Government buildings, the Irish Government approved additional funding so that the programme could continue. That experience was invaluable. I remember we had a bunch of balloons emblazoned with *Choice not charity* that were tied together and looked like one big ball, which we untied after the delegation was granted an audience and the balloons soared into the air. We held on to some of the balloons and handed them out to passers-by. That's how the programme continued. It was fantastic.

Even while I was in Belgrade, and before Ireland, I'd read about Adolf Ratzka[36], who published a magazine on independent living and who is considered the "father" of independent living in Europe. Reading his articles, I had the impression that I'd known him for a long time. I finally met him in Dublin when the Dublin Centre for Independent Living invited him as a guest to an event called the Pride Parade. He was still at the early stages of the social model of disability, which was a form of protest against the medical model, and where at one time it was considered that people with disabilities had to meet and make decisions on their own, without the presence of people without disabilities. The Dublin Centre for Independent Living, however, tried to include people without disabilities who were enthusiastic and wanted to support our struggle for independent living. Adolf was completely taken aback when he saw people without disabilities at the meeting partaking in the discussion equally, because he felt that was wrong. Then they asked me to take him to dinner in the evening and discuss it with him. I tried to explain to him the mentality of the people in Ireland and why it was important to have as many allies as possible. After that his attitude changed completely compared to the attitude he arrived in Dublin with and the one he had approached the Irish with.

That day a walk had been planned by people with disabilities from the Centre, but also from other organisations, which was to go through the main square and end with a small conference at the Mansion House (official residence of the Lord Mayor of Dublin). It rained cats and dogs (which is hardly a surprise in Ireland), but despite that, at the agreed time, about seventy people with disabilities, assistants, and other friends gathered in the square, carrying banners, megaphones and the like, all in great spirits. We made our way in the downpour to the Mansion House without a care in world that most of us were soaked to the skin. The conference was a great success. Both Adolf and I took to the rostrum, which we were later told was very inspiring.

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[36] Adolf Ratzka, PhD., pioneer of the independent living movement in Europe after moving from the United States to Sweden. Further information at: http://www.uloba.no/SiteCollectionDocuments/Independent%20living-seminar%20140614%20Adolf%20Ratzka.pdf (Ed.note).

Can you tell me how is it that barely thirty people turned out in Sweden and that seventy turned out in Dublin in the lashing rain? You can't get ten to turn out here unless you're protesting for a large sum of financial assistance or some other benefit.

Indeed, Adolf couldn't help but wonder how barely twenty or thirty people turned out in Sweden on a glorious sunny day, and how so many groups of people gathered in Ireland on that rainy day, having a great time in the process. I think that this was a phenomenon known as benefit trap, because when you fight for various state benefits, people are lulled by those benefits and are under the impression they have all that they need. So, for example, you have home help, or assistants, but never mind the fact that transport is inaccessible, and people with disabilities will no longer have a need to leave the comfort of their home. In Ireland, people with disabilities had very few opportunities to live independently, and as in any revolutionary movement, you have greater motivation to fight to for your rights. The group of people gathered at the Centre for Independent Living at the time had immense enthusiasm and motivation, and as my friend Martin put it, you could feel a "buzz in the air," a special energy that enveloped us at training seminars, meetings and when socialising. At first, there was only the Centre in Dublin, and when funds for independent living began to be allocated, coupled with state involvement, then local centres for independent living began to spring up. I don't know how many centres they have in Ireland now, because having clinched that "victory", Martin, who was the "spiritus movens" of the entire movement, felt that the Centre no longer needed to provide personal assistance, and instead the Dublin Centre for Independent Living (CIL) was founded[37], which dealt with specific support structures for Dublin exclusively, and eventually leaving the provision of the service to the Irish Wheelchair Association because it was a highly professional organisation providing a range of services with well-organised accessible transport and other resources, all contingent on the service being continued in line with independent living philosophy principles.

The CIL of Ireland continued to engage in advocacy and the establishment of local centres. The CIL's core remit was indeed advocacy work and lobbying the state on policy vis-à-vis persons with disabilities. In addition, we conducted research which demonstrated what different support structures meant for people with disabilities.

Was independent living discussed at EAMDA meetings or did you first learn about it when you went to Ireland?

Well, not in so many words. The EAMDA Assembly has always had a section dedicated to medical issues and far more importance has always been

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[37] Centre for Independent Living – CIL (Ed.note)

attached to it due to ongoing neuromuscular disease research. Then Evald Krog from Denmark and I pushed to have a part of the conference dedicated to social issues where we discussed support structures that would give people a degree of independence from their family and so on, but it was never referred to by that name. So, I learned about the concepts in Dublin even though truth be told I was already familiar with and had experience of them, it’s just that I wasn’t au fait with the terminology. So, we started building new terminology at that Symposium in 1995 in Dublin, which was a great event. Everyone was thrilled.

When did you learn English?

I studied English in comprehensive school, then improved it a lot through working at EAMDA, because the working language was English, so all correspondence, as well as meetings and conferences were held in English. When I went to Ireland I also used English all the time but mostly formal English that was appropriate for working in an organisational setting. However, I had a problem with the vernacular because I didn’t know the words used around the home or for household tasks, for example, the word for meat tenderiser, onion chopping board and so on. I’d never had occasion to use words like that at a conference. It was during my time there that I learned the vernacular that I needed for everyday life. For the first month and a half in particular, my brain was fried from the concentration. On one piece of paper I had clothing expressions written out (*vests, tights, leggings*), as well as verbs such as *pull up, tighten, straighten*, etc. I kept that piece of paper on the wall next to the bed so that I could explain to my assistant how I wanted to dress and explain other daily activities. If I needed assistance during the night, I was supported by an assistant that Flo had and who lived in the same apartment with us.

How did you spend your time in Ireland?

Like I said, at first Mimica and I were there to help Flo manage everyday life on her own with the help of assistants.

When Flo moved into the apartment, there were occupational therapists, one of whom came to assess what was needed for the adaptations so that she could use the apartment unhindered. So, for example, she got a special shower chair, a bed transfer crane and so on, which was all provided by the healthcare fund, which also covered the costs. One of the institutions also had a wheelchair assessment section, where wheelchair users could check whether a certain model of wheelchair suited them, whether they needed a wider or narrower one, what type of wheelchair to use and whether any modification was needed, for example, an extra headrest.

So we helped her learn that she can organise and give instructions to the assistant if she wants laundry put in the machine, the apartment tidied, and to prepare meals for herself, and that she shouldn't only be eating frozen food, which does not need to be prepared. She learned how to make "moussaka"[38] and it later became her favourite dish to prepare when she had guests.

The following year, when I went to Ireland again to manage the *Operation Get out* project, the Centre rented an apartment for me, so I lived alone in my "apartment," which was a ten-minute walk from Flo, and we continued to hang out with and visit each other. I had two assistants at the time. One assisted me with personal needs and around the flat, and another girl assisted me at work and spent time with me in the office. The assistant who helped me with my personal needs also stayed overnight with me in the apartment. I went to work by train, which was accessible, and part of the way on foot.

Would you tell me about how Flo ended up throwing parties?

Flo was confused at first, and when she realised that she could now decide for herself and that she didn't have to ask anyone for anything, that she could invite friends over for a drink or a party, she went full steam ahead because it was something completely new for her. While Mimica was still with us, we took her to the city by train for the first time. She'd never taken the train before because her sisters always brought her by car. That first night out in the city we went to the cinema, then to dinner at a restaurant and, of course, we took the train home. She was so exhilarated that when we got home she just said: - Oh, dear me, I need a hot whiskey - to take the edge off the excitement. It was the first time in her forty years that she could use public transport on her own, go to the cinema and have dinner at a restaurant, without being taken there by her sisters. She started inviting friends over and throwing parties. Its standard practice in Ireland for everyone who comes to a party to bring their own drinks and snacks, because as she used to say: - We are in the independent living and we are poor. With the Irish fond of a drink, everyone gets a few drinks in to warm themselves up (because it's cold and it rains all the time): then the divilment starts! And so, one night, she rang up the fire brigade to see if the firefighters fancied popping in for a drink because there were only girls at the party.

Flo and I visited each other every day. As she was constantly cold, as was I, she carried a hot water bottle in her lap and a blanket over her knees and the first thing she'd ask when we got into the flat was: - Will we have a hot whiskey? Then I'd do the very same when I'd call over to her: fill the hot water bottle, put it in my lap, put a hat on my head, it didn't matter how hard the wind blew, and throw a blanket over my knees and when I'd get to her place we'd drink a hot whiskey again to warm up. I'd often stop by her place on my way

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[38] Moussaka is a dish made of potatoes and minced meat

home after work. We had a great time. I also went to visit her sisters and they became like family to me.

I was also very close with Gráinne, whom I worked with, and Judy, who, unfortunately, passed away two years ago (2014). This is the woman I told you about who was the Secretary General of EAMDA and who invited us to come to Ireland. She was a lawyer, and her husband was a judge who took me to court to see what a trial looked like. She was terrific, she often invited me over to dinner, or for Christmas Eve or Easter lunch. They accepted me as one of their own and I really felt that in a way it was a home away from home. After I returned to Serbia, Flo used to ask on the phone: - Gordana, when are you coming home?

What other activities took place in the Centre?

Various workshops and other activities were organised that were not necessarily related to matters of personal assistance, rather they gave people an opportunity to socialise and meet up and paved the way for a special bond and convivial atmosphere to take hold in the group, strengthening and giving it impetus to lobby and fight for its rights. Famous musicians and actors attended and delivered these workshops in a volunteer capacity.

There were also some comic scenes. We had one workshop on musical composition that Bono[39], lead singer of the band U2, was supposed to hold. Martin arrived after the workshop had already begun, and on his way in he said to the first chap he saw: - You there, young fella, go ahead and put on the kettle. The young fella, who was in fact Bono, replied unperturbed: - Sure, and left [to make the tea]. The others were gobsmacked and said to Martin: - Have you lost the run of yourself, do you know who that is? - Who? Martin asked. They said: - That's Bono. Later, Martin recognised him by his voice, and for a long time after the story did the rounds about how Martin sent Bono out to put on the kettle for him.

Flo and Gordana with Christy Moore

Christy Moore, a famous Irish singer-songwriter, also delivered a similar workshop on musical composition[40], and I loved his ballad “The Voyage” the most. We later adopted that ballad as the theme tune for our Center in Serbia when

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[39] U2’s lead singer, Paul David Hewson, better known as Bono (Ed.note)

[40] Christy Moore, famous Irish singer-songwriter (Ed.note)

we founded it, because it talks about a voyage, which we associated with independent living.

We also organised fashion shows of famous designers, where people with disabilities were models, so I “took to the catwalk” to model some sweaters at one of the shows.

Mimica and I also took to the stage in a theatre play organised by the Muscular Dystrophy Association of Ireland, through the “Horizon” programme, where young people with disabilities learned about the media, how to produce radio shows, television reports and finally about theatrical art.

Everything was very professional. The director was a woman who was a director by profession and the music for the play was composed by a guy with muscular dystrophy. The play was called the “Children of Lir”, based on an old Irish legend about children who had lost their mother and whose stepmother put a spell on them turning them into swans, with the curse that they would only take human form again when the first church bell sounded in Ireland. I played two parts, the ghost of the dead queen, who shows up to save the children from a violent storm, and a druid (a Gypsy woman fortune-teller) who told their stepmother that she would never have children of her own. The costumes for the show were designed by a famous painter, who later gave us sketches for those costumes as a gift. The play was performed at the City Arts Centre, in a circular space, where the audience sat in the middle facing the stage where the individual scenes played out. The most beautiful thing was that these children were portrayed by young men, electric-powered wheelchair users, aged seventeen to twenty, and when the spell was cast they appeared as swans with wings mounted on the sides of their wheelchairs and swan heads mounted above the headrests, and they circled slowly in their wheelchairs, through a mist, as if the swans were really floating. The swans maintained their human voices and sang beautifully, and they took human form when the first Christian came to Ireland, built a church and the first church bell rang. It’s a wonderful legend. All the actors were wheelchair users, except for Mimica, who had the only “walking” role, and played the part of courtier and keeper of the mirror of truth. The play can still be found on YouTube (“MDI Children of Lir”)[41].

The ideas and creativity from that era eclipse those found in Serbia today.

And you had training sessions also?

Yes, of course! There were training sessions for both beneficiaries and personal assistants, and the rule was that one of the beneficiaries (leaders) had to always be present at the training for assistants if, for example, the training session was being delivered by physiotherapists. I remember one training session where the trainer demonstrated the transfer of a “patient” to and from the bed. A bed that could not be approached from all sides was set up for the

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[41] https://www.youtube.com/watch?v=6kx8fkcCmBk&t=756s

demonstration. Explaining the transfer, the trainer said: - Of course, in a real world setting that bed would be positioned to make it approachable from all sides with enough room for one person to pass. The beneficiary who attended the training said to the trainer: - How do you know there'll only be one person in the bed? Laughter rang out around the hall.

Over time, enthusiasm waned there as well. As soon as they have a sense of security, preferential treatment, increased accessibility, accessible transport, an assistant, and are left to their own devices, then all interest in the disability movement and the efforts driving it forward is lost, save for a small number of people. You can't drum up interest among them anymore. But back then when I was working there, those were the golden days of genuine enthusiasm that I felt when we were establishing the muscular dystrophy organisation in our country because we had no blueprint to work from and we forged it all from scratch.

To pick up on your point about Martin having spent a good part of his life in the institution, did the people with muscular dystrophy that came to Zenica and Fojnica also live in institutions later in life?

Not usually. We have never had this type of institution, and even today there are only two residential care facilities for people with physical disabilities. The first one was opened in Bežanijska kosa. Unfortunately, no residential care facility has been established to cater for children and adults with intellectual disabilities. However, Ireland had numerous institutions of that kind called charity institutions and the disability movement was heavily involved in kick starting the process of deinstitutionalisation and of giving people with disabilities the opportunity to live in an open environment.

What path did the disability movement in Ireland take to ensure accessibility?

I think that Ireland borrowed from the English model because there had been a dynamic disability movement there for a long time. At that stage, the Irish had by and large adopted the standards that were valid in Great Britain.

There was no accessible transport, but, for example, there was a housing allowance that allowed you to rent an apartment and get a transport allowance. There was an awareness that you needed extra money for transport. Thus, relative accessibility standards had already been put in place. Most public buildings were accessible: Dáil Éireann and the Mansion House were accessible, as were other public buildings of culture, education and so on. But transport was inaccessible. We launched a campaign to lobby for accessible buses (Dublin Bus), and then a group of us queued to buy bus tickets. When a bus pulled up to the station it had three steps and a bar in the middle, so there was no hope of getting on. Flo, who was extremely eager, spent half a day at a bus station and as each bus pulled up to the stop she'd ask: - Can I get on? The driver would say: - Well, I don't think you can. But she didn't relent: - I bought a ticket, I have a right to get on, I insist. And the argument went on and on. The passengers on the bus were cheering for her for the most part. They offered to lift her on but she wouldn't hear of it. And when a bus would leave, she'd go back to buy another ticket for an accessible bus, and so the entire group took turns at the counter to buy tickets for a non-existent accessible bus. The ticketing clerks were at their wit's end, they called the director of Dublin Bus, we called the journalists and the television stations to demonstrate why bus transport is inaccessible. It was a huge campaign to organise accessible bus transport. Later, Dublin, like all major cities, modernised and bought low-floor buses that were otherwise manufactured in Northern Ireland but were not in service.

They also had the support of the Disabled Federation of Ireland (DFI), which is somewhat similar to the National Organization of Persons with Disabilities. Various associations were involved, and the DFI handled issues of general relevance. When the Centre was founded it teamed up with the DFI and together they advocated accessible transport, the personal assistant service and all the rest. That's how they managed to secure funding and get all those services included in the system.

Then we came up with the idea of organising a large-scale international conference on independent living, which we called a symposium. Why symposium? I don't know, I suppose to make it stand out from the run-of-the-mill conferences that were organised. I was the organiser of the symposium, in charge of planning the programme and communicating with organisations across Europe, because through EAMDA and my other contacts I knew various people throughout Europe such as John Evans[42], who I'd also heard of and I was able to get in touch with them all, as well as a number of people from America who were involved in having the ADA[43] enacted, for example Sid Wolinsky and others who I'd had contact with years beforehand. Logistics for the symposium were handled by other associates from the Centre. My colleague Gráinne and I put together the symposium programme, organised topics for discussion at the plenary session, and speakers, working groups, and set the objectives and expected outcomes for each group. The main topic of the symposium was "disability is not a burden on society, but an investment", and

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[42] Pioneer of the independent living movement in Great Britain. In recognition of his work to improve the position of persons with disabilities and pave the way for independent living, he was appointed an Officer of the Most Excellent Order of the British Empire (OBE). Further information at:
http://www.independentliving.org/25years2008evans (Ed.note)

[43] The Americans with Disabilities Act, passed on July 26, 1990, at the initiative of the disability movement in the United States, was the first national law to define discrimination on the basis of disability and accessibility standards and to prompt other countries to enact legislation. (Ed.note)

that’s where I first met Gerard Quinn[44] from Galway who had researched the costs of disability, a topic put forward for discussion for the first time at that symposium. Everything was organised with the utmost professionalism, and the symposium was held in May 1995 and was a resounding success.

We had booked a conference room at Jurys Inn Hotel in Dublin, only to be told that they had just started renovating it and that it was no longer available. We reached an agreement with the hotel to reduce the price and set up a tent for the symposium at the front of the hotel, which was heated and connected to the hotel. According to the programme we planned to organise the final part of symposium at Dublin Castle[45], a prestigious venue housing the main institutions of the Irish government, and our guest was a member of the European Parliament, a representative of the Republic of Ireland, a person with paraplegia, who was primarily involved in politics, without much interest in disability issues.

So, the symposium went ahead in the tent, which was hilarious with its heated corridors connecting it to the hotel where we availed of the restaurant and accommodation. The final session was held at Dublin Castle. Afterwards, we published a piece about the symposium, which we symbolically titled “From the Tent to the Castle”. It could also, poetically speaking, lend itself to a description of the origins and development of the Dublin Centre for Independent Living. To this day I am extremely proud that I managed to put a programme in place for and organise that great international forum, with the help of many people from CIL Dublin of course.

How would you rate your work in Ireland?

The time I spent in Ireland had a tremendous impact on my later life and work. I experienced a whole new country, culture, mindset and learned a lot about the philosophy of independent living, human rights, and the personal assistant service. On top of that I made a lot of friends, some of whom became part of my family. That’s how I always felt about them and vice versa. I used to say that Dublin or Ireland is my second home.

That’s where I learned the terms and theory of independent living and its underlying philosophy, though for all intents and purposes it had been a part of my life beforehand. I did a lot during the four years I spent there, including working on the magnificent “Operation Get-Out” programme, which gave me a front row seat to the process of transitioning from institutional living to

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[44] Gerard Quinn is Professor Emeritus in law at the National University of Ireland (Galway), and Director of the Centre on International Disability Law & Policy. (Ed.note)

[45] Dublin Castle (in Irish: Caisleán Bhaile Átha Cliath) was the seat of the British government’s administration in Ireland until 1922, and is now the main Irish government complex. Most of the complex dates from the 18th century, though a castle has stood on the site since the 12th century. (explanation provided by the interviewee)

independent living and just how challenging and difficult it is to master. On the other hand, I was happy to be able to leverage my life experience to mentor a number of people to navigate this process and learn the basic things essential to everyday life, to gain self-confidence and encourage them to carry on living with a new lease of life in keeping with human dignity.

In Ireland, I had the opportunity to gain mentoring experience, give lectures in a new field and learn how you can help raise awareness in others about their attitudes towards disability issues.

I campaigned for the rights of people with disabilities in Ireland, commented on the laws, met with many Irish government officials, including the President of Ireland Mary Robinson[46], protested in front of Government buildings, was part of a research team, was involved in the "INCARE" personal assistance programme[47] and passed on my knowledge and life experiences to beneficiaries and personal assistants. I think I accomplished a lot in terms of motivating people with disabilities and getting them to start advocating their rights and campaigning to be the architects of their own life.

Gordana, Luka, Mimica and Dimitrije Gligorijević in Dublin, 2004 next to a statute of the great Irish writer James Joyce

One of my greatest successes was planning, organising and bringing about the large-scale symposium on independent living and liaising with participants from all over Europe and the United States of America. That symposium met with a powerful response, where for the first time the topic of the cost of disability was raised, including the viewpoint that disability is not a burden and should instead be viewed as an investment for society. I met many people, wonderful activists and campaigners in the disability movement, I learned from them, and I believe that they too learned from me.

That connection to Ireland remains to this day, although some of my closest friends in Ireland are no longer with us, but

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[46] The first woman to hold the office of President of Ireland, from 1990 to 1997 and United Nations High Commissioner for Human Rights from 1997 to 2002. (Ed.note)

[47] The literal translation does not reflect the purpose of the programme, which in fact covered the provision of support (explanation given by the interviewee).

for me they are always there. Ireland was one big learning curve for me, a part of my life that was completely different to what I'd known up to that point, a life in which I regained the freedom I had before muscular dystrophy which significantly reduced my physical abilities and movement. Of course, the environment was much more accessible, which allowed me to live like every other person in Ireland.

And when I'd finished working in Ireland, I continued to visit time and again, giving lectures on various topics, attending various conferences and meetings. In 2002, to mark the Dublin Centre's anniversary, I also received special recognition for my outstanding contribution to the development of the independent living movement in Ireland, and they say that I "left a huge mark" on their disability movement through my work and achievements. It's a great nation. When I returned to Serbia I organised study visits to Ireland on several occasions for my colleagues from Serbia and Bosnia, the purpose of which was to give them an insight into the workings of the movement in Ireland and its achievements. They always returned extremely satisfied and all the richer for the new experience and new knowledge, keen to roll up their sleeves and start working in the Center for Independent Living in Serbia. On one of the many trips to Ireland my Dublin friends threw a farewell party for us, and our colleague, Vera Knežević[48] who travelled with us, said: - Good lord, it's crazy how much they love Goca[49]. My friend Dimitrije Gligorijević[50], who was also there, said: - Well, we love her too because she's one of us!

Despite the enormous pleasure of going to Ireland, it was also quite a stressful and exhausting time for me. This all took place at a time when Serbia was under sanctions and Belgrade Airport was closed. So Mimica and I would travel by bus all night to Budapest, wait for the airport to open and then to board a flight to one of Europe's transport hubs (London, Amsterdam) because there was never a direct flight to Dublin. Mimica would wait for me to go through customs and then I travelled the rest of the way on my own because the Centre in Dublin didn't have the funds to pay for two tickets. I had to explain to the airport support service how to get me on the plane, unfold my wheelchair and take it to the hold. Throughout the flight I'd pray to God that all the parts of the wheelchair would reach the airport I was going to and that the wheelchair would be waiting for me (at the gate), assembled and that I'd be taken straight from the plane and into the wheelchair. I'd continue on with my hand luggage hanging on the wheelchair and wait for the onward flight to Dublin. The hardest part was if I had to go to the toilet in the meantime, and there was no one to help me. In that case I'd go to the entrance to the women's restroom and size up which passenger would be best suited to help me. It was dreadful.

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[48] At that time, Director of Belgrade Handicap International office (Ed.note)

[49] Gordana's nickname (Ed.note)

[50] Dimitrije Gligorijević (1958-2020) (Ed.Note)

On the onward flight to Dublin it was the same routine all over again and I used to be so relieved to finally arrive at Dublin airport with the wheelchair and my luggage fully intact. A friend in Belgrade (who did not have a disability) used to say to me: - You're mad, I wouldn't go to Niš alone, let alone to Dublin. I don't think I'd dare to do something like that again, but who knows?

When did you return from Ireland?

After the symposium was held, in April 1995. The British humanitarian organisation OXFAM, which worked in the region, announced a job vacancy for Deputy Head of the Belgrade Office, so I applied and was invited to an interview in Belgrade. Since I had been in Ireland for almost four years at the time, I was well versed in human rights issues and the English terminology specific to that field. So, of all the candidates who applied for that job vacancy, I spoke English the best, plus I had an appreciation of various minority groups and the like. They asked me if I could start working on March 1st but I couldn't accept it because I was still putting plans in place for the symposium. They agreed to wait until I finished my work in Ireland and so I started working at OXFAM in late April 1995.

It was a great opportunity for me to return to Belgrade, to be paid for my work and to keep in touch with the English language. At that time, OXFAM concerned itself mainly with refugees arriving from Croatia and Bosnia, and to some extent with humanitarian aid for people with disabilities (medical supplies, nappies, etc.). Their offices were fifteen minutes from my apartment, so I could "walk" to work without any need for transport, which made the commute significantly easier. It was a magnificent and very professional organisation where I learned a lot. Before starting the job, I spent ten days in Oxford at an orientation course to learn about the organisation, its work, and the principles underpinning its work around the world. When they hired me they also provided me with the means to hire a personal assistant which was unheard-of in Serbia at the time. By the way, most of the staff at OXFAM were highly educated because they were people who, due to the sanctions, could not find a job in their line of work or their salaries were irregular or meagre.

The organisation ran special schemes for refugees in refugee centres, where self-financing schemes were organised, and various machines were procured so that businesses could be started, or land would be leased for those people to grow assorted vegetables, keep livestock, etc. That scheme was managed by a colleague who was a social worker in one of the institutions in Belgrade.

As the deputy head of the office in Belgrade, I was out in the field visiting refugee camps and assessing what was required to further develop and improve those schemes. I can recall the scene when I went to the Varna refugee camp near Šabac[51] for the first time together with a colleague who ran that scheme. We travelled in an ordinary passenger vehicle that OXFAM had and when we arrived at the camp the driver took my wheelchair out of the boot, picked me up and placed me in the wheelchair. Children from the camp swarmed around, and they, like everyone else, watched and wondered. When we entered the director's office, my colleague introduced me and said: - Here, this is my new boss! Everyone was gobsmacked. How could I, a person with a disability in a wheelchair, be the head of such a large foreign organisation, because of course notions about people with disabilities were far different.

At that time, I managed to get them to include support for people with disabilities in the Emergency Programme which, in addition to providing humanitarian aid, also included several other activities. The first projects we financed were programmes for removing architectural barriers in Leskovac and Zrenjanin. Then I organised a conference on disability issues in Belgrade, entitled "Is there a disability movement in Serbia?". The topic caused indignation among disability organisations because they believed that their mere existence as standalone organisations with their different objectives and activities, when taken as a whole, constituted an umbrella disability movement. However, a lot of organisations turned up, as well as some social protection experts, and a very heated discussion ensued. That was the first time I spoke about different models of disability and I was the first person in Serbia to talk about the medical and social model of disability. Thanks, of course, to the knowledge and experience I gained during my time in Ireland. At that seminar, I also made the acquaintance of sociologist Gradimir Zajić[52] who worked at the Social Policy Institute and later for Handicap International. He was fascinated by the whole story and cooperates with us to this day.

You worked on programmes for people with disabilities?

After a year and a half of working at OXFAM, a job vacancy opened for Regional Disability Adviser because they wanted to promote the issue of disability in other OXFAM offices in the region, which apart from Belgrade, were also located in Bijeljina, Banja Luka, Goražde, Mostar, Sarajevo, Prishtina, Skopje and Tirana[53]. That's how I became regional disability adviser at OXFAM, travelling around the region, visiting various organisations and checking whether there were programmes in place for people with disabilities and whether they needed to be improved or implemented where they didn't exist. One of my early successes was making all OXFAM offices in the region

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[51] A small town west of Belgrade (Ed.note)

[52] A sociologist who at that time worked for the Belgrade office of the French humanitarian organisation Handicap International. (Ed.note)

[53] Covering Bosnia and Herzegovina, Macedonia, Albania and the province of Kosovo (Ed.note)

accessible so that people who had mobility difficulties could access them. And it did happen! Where possible, ramps were installed, and in Sarajevo they even rented another office because the one they were in could not be adapted. In each of the offices I first tried to sensitise staff to disability issues by holding workshops on disability, the rights of people with disabilities, and the problems they have, including those related to independent living. I also helped the staff to liaise with disability organisations, which was more difficult for them, whereas I had a large number of organisations at my fingertips because I'd been cooperating with them for many years through the Muscular Dystrophy Association.

I remember being invited to Goražde, where the head of OXFAM's office complained that he couldn't reach any agreement with disability organisations because at the end of each discussion they'd say: - You're not a person with a disability and you don't understand that. I went there, we had a meeting, I knew some people from before, I told them about my experience and the experience of other people with disabilities and I managed to get them to agree to start doing something together with the support of OXFAM. The war in Bosnia and Herzegovina had just ended on paper with the Dayton Agreement[54], but the ramifications of the war were palpable everywhere. The lights would go out six times a day. And in the evening there was no street lighting, only car headlights illuminated the road. It was a case of setting off on your journey and it was anyone's guess where you'd end up. The driver, my assistant, and I travelled to Goražde. We overnighted in private accommodation because the hotel had been turned into a refugee camp. During the day, the driver scouted the route we were to take, while I was in the office all day. In the evening when we retired to the accommodation, the head of the office gave us a walkie-talkie so that we could have a line of communication to the office staff. The driver carried the walkie-talkie, and it always had to be on, you had to be reachable twenty-four hours a day so that they could check where we were.

It wasn't until we left in the morning that I saw that only half the house was intact - the other half had been demolished. They rented the part that was intact to foreigners and others to earn some money, while they lived in the demolished part covered over with some nylon. In the morning, two women attired in traditional clothing for Muslim women in Bosnia timidly offered us some coffee, and it was clear as day from our accents that we were from Serbia, which made for a very odd situation when we left because neither they nor we knew what to say. It would be bad manners not to say thank you, or not to wish someone a safe journey or stay, and yet you have to say something along those lines. The women were terrified of us, as if we were going to slaughter them on the spot, and we were afraid of them.

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[54] Signed in Paris on December 14, 1995. (Ed.note)

How did you meet Suvad Zahirović?

I met Suvad, Sanja, Fikreta[55] and other colleagues from the "Lotos" Information Centre for Persons with Disabilities in Tuzla when I visited the OXFAM offices in my capacity as regional adviser, one of which was in Tuzla. The "Lotos" Information Centre was an organisation founded in 1997, supported by OXFAM and they were already working on many issues concerning the rights of persons with disabilities, publishing and was one of the truly progressive disability organisations in Bosnia. I visited their Centre and was extremely impressed with what they were doing.

I remember Suvad in particular, who is a blind person with an incredible sense of space and surroundings, and who graduated from physiotherapy college and then studied political science in Belgrade. We both attended OXFAM's large regional conference on disability issues organised in 1998. The conference was held in Bosnia so that participants from the entire region could attend. I suggested that it be held in Fojnica, which I knew and loved as the birthplace of the Muscular Dystrophy Association of Yugoslavia. Participants came from Bosnia and Herzegovina (from both entities because parts of the Federation and Republika Srpska had already separated at the time), from Serbia, Macedonia, and Albania, including participants from OXFAM's Oxford office. We held the conference in a relatively new facility that had been a rehabilitation centre for various illnesses before the war. Word quickly spread about the conference because it's a very small town, including word that participants had come from both Republika Srpska and Serbia. Fojnica is located in the Federation, in an area that witnessed heavy fighting which had a profound effect on interpersonal relations and stirred up uneasy feelings around nationality.

The conference was, of course, attended by participants from "Lotos": Suvad, Sanja and others. The first day of that conference went well, and after dinner, as there was no place for people to go out, most of us congregated in the big hall where the conference was held and we chitchatted, reminiscing about events of yesteryear because some people already knew each other from before, and then it occurred to someone to start singing and then everyone sang songs from countries where they had been participants. The best thing was that those of us from Serbia sang Bosnian sevdalinkas[56], and people from Bosnia, Suvad included, sang songs from Serbia. At some point, a young man in a wheelchair suddenly came in and asked who was from Belgrade. At first, without any hesitation, I said I was, guessing that maybe there was someone in Belgrade he'd like to get a message to or something else because the phone lines were down for the most part. He kept repeating the same question. I answered, as did

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[55] Sanja Zahirović, Fikreta Hasanović (Ed.note)

[56] Traditional Bosnian songs expressing both intensity of love and melancholy (Ed.note).

both my assistant and the driver. It was getting a bit strange at this stage and we asked him if he needed something, but he started shouting that we don’t belong there and that we as “Chetniks” have to leave the venue at once, otherwise he’ll return in half an hour and if he still finds us there, he’ll kill us all. This made for a most unnerving situation because it was still a time when people carried weapons a lot, even hand grenades, and we couldn’t tell if he was carrying a weapon, not to mention the fact that he was incensed and angry. I believe he had his reasons, perhaps someone dear to him was killed or wounded in the war, because in the meantime that rehabilitation centre became a centre for war related disabilities.

Those in the hall were struck with fear, especially those from Republika Srpska and ourselves from Serbia because our passports were at reception, so the names of the participants were common knowledge, including where they were from and what room they were in. We quickly called it a night. They gave me the option of moving to another room to be safer. I said I wasn’t going anywhere and that I was staying in my room come hell or high water, and then Suvad said he was going to “keep watch” and he sat with us all night. When someone knocked on the door he’d ask who it was and what the password was, because the participants from England and some others from OXFAM’s offices started turning up to find out what had happened. The next day we had a meeting to decide whether to continue on in Fojnica or to go to Sarajevo given that the conference was supposed to last two more days, and in the end we decided to go to Sarajevo. We had to practically “evacuate” from Fojnica travelling in a convoy, with an OXFAM jeep equipped with walkie-talkies at both the front and rear of the convoy.

When we decided to leave Fojnica I burst into floods of tears, not out of fear or unpleasantness, but only because then did it strike me that the country I grew up in had disappeared. I saw Yugoslavia as my homeland. And then I suddenly realised that it was no longer the same, that the war had changed everything, including the people. They wanted to discharge that guy from the rehabilitation centre the following day. I went to plead with them not to because he’d probably experienced something deeply traumatic during the war.

Among other things, that is how Suvad and I became not only colleagues, but also dear friends. Since then, we have continued to collaborate on many other projects and to keep each other’s company, right up to this day, for the best part of twenty years.

What other recollections do you have from your time working at OXFAM?

I learned a lot at OXFAM: a professional approach to work, the workings of an organisation, I travelled throughout the region, including Albania, I went to Lebanon, to Georgia, to Bangladesh.

In Bangladesh I held workshops for people with disabilities and the staff of their office in Dhaka in English, which the associates interpreted into the local language. The workshops were held in the so-called “rural” part of Bangladesh, which is difficult to describe, because Bangladesh’s entire landscape is rural. Picture this: I’ve to give a talk about the human rights of people with disabilities, how they have to fight for a better quality of life, create a movement to campaign for the rights of people with disabilities, all in surroundings where people have nothing to eat or wear, with no roof over their head. It was quite the challenge to adapt the story to those circumstances, without looking like a fool and raising false hopes. Nevertheless, I managed and we understood each other well.

I also visited their rehabilitation centre where I saw people with spinal injuries learn to function in a “new” life, using a special type of “wheelchair” that resembled a board with wheels screwed onto it, something similar to what children in Serbia used before skateboards became available, because countryfolk do almost all their daily chores sitting on the ground. They learned how to move on those boards by pushing off with their hands, how to prepare food, get dressed, etc.

I remember that in that rural part there was prison-like accommodation, void of anything, with water available from a communal outdoor drinking-fountain. As a “special” guest, I was given a room that supposedly had a bathroom: a tiny room with a toilet on a high pedestal and a large barrel in the corner mounted with a water pipe and tap. I must admit I didn’t use this “sink” because I was in constant fear that my soap or toothbrush would fall into the barrel. I used the communal outdoor drinking-fountain instead. Above the bed was a makeshift mosquito screen with a layer of dust on it, which we weren’t too keen on using, but we quickly changed our tune when we saw spiders and various other creepy-crawlies on the walls and ceiling.

Before leaving for Bangladesh I didn’t get a malaria vaccination, which was otherwise the rule at OXFAM when travelling to such areas. During the night I opened the window and in the morning I was covered in mosquito bites. The office staff “comforted” me with the fact that the incidence of malaria was not too high that year. There was a bottle of water on the desk in the office that said “arsenic free”. I read it and enquired: - Excuse me, am I right in thinking that this is arsenic-free water? Nods all round. So, arsenic in water does exist! Then they explained to me that arsenic occurs naturally deeper underground, but because the area is prone to flooding and heavy rainfall, the water penetrates to the arsenic which begins to dissolve, resulting in the water at wells and drinking-fountains and other sources also containing arsenic, which the locals are accustomed to. They recommended that we limit our fruit intake to bananas, which could be peeled, we didn’t drink anything, save for that arsenic-free bottled water or some tea. But it’s hardly foolproof because dishes are washed in that arsenic contaminated water, bread is kneaded with it, so it’s much of a muchness. They eat food that is immensely spicy because that spice causes the stomach to secrete juices that kill bacteria, guarding themselves against infections. So, we lived there for five days on a diet of bananas and on the flatbread they make in India. My assistant wanted to take a hot shower so she asked me to ask the host if there was hot water. The man I approached enquired as to what we needed hot water for - was it for tea? In Bangladesh, the term hot water is associated with tea, not with showering.

In Beirut, Lebanon, I was surprised at how inclined people with disabilities were to take action. The buildings didn't have elevators and they used makeshift "cranes" similar to the pulley lifts used by bricklayers, which were raised and lowered with ropes. One day they took me to visit one of their residential care institutions, which was in a different part of the city from where we were staying. They explained to me, without any fanfare, that the only thing that mattered was that we got there by a certain time, while there was a lull in fighting, because after that shooting would resume from one end of the city to the other. They even organised protests in that "open" space and stayed there all day in the crossfire to demonstrate how the fighting handicapped people.

Thanks to OXFAM, I visited places in the world that I'd never have seen and found people with disabilities there to be much more motivated, with a much more serious plight on their hands, to have a striking sense of unity and willingness to take action to improve their position. I talked to them a lot, shared my knowledge, learned from them about the conditions that people can live in and we always understood each other well, regardless of the language we spoke. It was a most valuable experience.

I also recall working at OXFAM during the bombing of Belgrade in 1999. OXFAM, like other international organisations, kept a "low profile". By that I mean they went about their business discreetly because the prevailing public sentiment was anti-Western. However, we did provide some emergency relief assistance and they made enquiries with me as to what people with disabilities would need apart from the standard medical aid kit. Based on my own experience, I devised a special "aid package" for people with disabilities. Given that I lived on the third floor in a building where the elevator, which we weren't allowed to use, worked only sporadically, and where electricity outages were frequent, I was house-bound without any information about what was happening. So I devised a kit that, in addition to toiletries (toothpaste, toothbrush, nappies, pain relief balm, gauze and all the rest), also included a hot water bottle, a portable gas stove with a spare cylinder and a flashlight that had two neon bulbs and one main beam and a radio. When there was electricity you could plug it into a charger, and when there was no electricity it ran on batteries. That battery was really important to me when the electricity went out, when I was home alone, because I was petrified of using candles or a gas lamp, which could turn over and ignite, and I would have been helpless. All these items served a significant purpose, because you can make soup or tea on the gas stove, you have lighting, and the radio was also important because it allowed me to keep abreast of events in the city. The people from logistics were dumbfounded by my proposed inventory, but they saw the method to my madness once I explained everything. So, in fact, this kit also doubled as a means for me to educate my associates about the needs of people with disabilities in wartime.

We distributed those kits to associations in Belgrade, and they delivered them to their members, providing us with lists of the recipients of that aid. Regrettably, even in those circumstances, people sought to take advantage. I found through random follow-up phone calls that many people who were on the lists did not receive their kits. Instead some of those kits found their way onto the stalls of market traders.

Nonetheless, I was happy to have devised something that was certainly useful, and that helped people who, like myself, were house-bound, even though I had no prior knowledge of what ought to be included in humanitarian aid for people with disabilities in conditions of war or similar situations. It was just intuition.

I loved working at OXFAM because I could see a direct benefit for the people I worked for and saw that disability is a universal issue, the same for world over. All the people with disabilities that I have met, both in developed western countries and in impoverished parts of the world, have faced the same difficulties and challenges and society's attitude towards them.

Did you spend the 1999 bombing campaign in your apartment?

Jelena Mitrović, who was studying in Belgrade at the time, lived with me and assisted me. After ten days, Jelena went to visit her parents in Kruševac, and since I couldn't function physically on my own, Mimica came with Luka, who was not even four years old at the time, to be with me on the third floor of a building where the elevator was mostly out of service and took care of both of us. On May 6th, a bomb hit the house across the street, there was minor damage to the building and there was no electricity or water. Given that staying on in that apartment was no longer an option, we went to the one-bedroom rented apartment in Zvezdara where Mimica lived. I stayed there for three weeks until my building was repaired so I could return to my apartment.

When did you get involved in the topic of gender equality?

I first encountered the concept of "gender" when I started working at OXFAM as the issue of gender equality was one of the main principles of OXFAM's work and the promotion of equality between women and men. They had a recruitment policy that encouraged job applications from women and persons with disabilities. Before starting work at OXFAM, I had to go through an "induction" period and complete a management course in Oxford, an integral part of which was learning about gender policy. Until then, I had no idea about gender, nor did I ever think about it, and, of course, through OXFAM and their publications, I began to understand the concept of the different gender roles that society gives to women and men and what the consequences are. By that I mean I began to understand discrimination on the grounds of sex, discrimination against women. In fact, that's how I came to realise that women and girls with disabilities face twice the amount of discrimination and that the obstacles faced by women and men even with absolutely the same type and degree of disability are by no means the same. Women with disabilities are in a far more precarious position than men with disabilities. Their discrimination is proportional to the severity of their, in particular physical, disability because a woman is expected to be a sex symbol, a good wife, mother, housewife and to take care of both her husband and other members of the household. It is quite the challenge for women with a high degree of disability and requiring someone else's physical assistance to meet society's expectations. The bar is set much lower for men with disabilities. It's routine for a woman or someone else to take care of him, where only standing, financial contribution to the family and, of course, masculinity counts.

At the time I also watched the magnificent documentary "Visions and Voices"[57], which explores the participation of women with disabilities at the Fourth World Conference on Women in Beijing in 1995. Despite the UN Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) coming into force in 1981, women with disabilities were not recognised as a group that was particularly discriminated against among the female population also. For the Fourth UN World Conference, women with disabilities from all over the world prepared specially to participate in a non-governmental forum that ran parallel to the conference. However, the conference venue was completely inaccessible for women with disabilities who therefore couldn't take part in the work of the conference. As a sign of protest, women with disabilities held a protest in the central zone, where the conference was being held, to highlight the fact that women with disabilities are still women who share all the problems that women without disabilities have, and many more due to their disability. The protest met with a powerful response, with Madeleine Albright, the then US Secretary of State, making her closing speech in the main marquee designated for women with disabilities, thus acknowledging their fight for equality among both women and people with disabilities.

That same year, 1995, I proposed that the book "We Can Make It"[58] be translated and published, which recounted stories about the lives of women with disabilities from different parts of the world, and we added several stories of

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[57] "Visions and Voices" is a documentary from 1995
(Source: https://www.youtube.com/watch?v=adfHKfZdvzI) (Ed.note)

[58] See publications by the Belgrade Center for Independent Living Serbia. (Ed.note)

women with disabilities from Bosnia and Herzegovina, Serbia and Kosovo. The book promotion and screening of the documentary "Visions and Voices" was held at the Belgrade Cultural Centre and drew a great deal of attention. This was the first time that double discrimination against women with disabilities had been discussed publicly. We subsequently published two more publications, "Obstacles to Equality - Double Discrimination against Women with Disabilities" and "Violence is the Death of the Soul" in 2004.

That's when I devised and held my first workshop on issues of women with disabilities. As I didn't know enough about discrimination against women in general, I invited Marina Blagojević[59] to deliver the workshop with me. She was suspicious because she wasn't familiar with disability issues but we agreed that she'd talk about discrimination against women and I'd talk about people with disabilities, so that we could get an appreciation of the issue from both angles. Two years ago when I met her at the conference of the Women's Platform for the Development of Serbia, she said that she'd never forgotten that workshop because it opened her eyes to a "new world" inhabited by women with disabilities.

You also organised the first conference of women with disabilities in the region?

Yes, inspired by the film about the protest of women with disabilities held in Beijing at the IV World Conference on Women, and my experiences from workshops on women with disabilities, I put a proposal to OXFAM to organise the first regional conference on issues of women with disabilities. The proposal was accepted and the conference was held in April 2000 in Ohrid, Macedonia, and was attended by about seventy women with various disabilities from all over Bosnia and Herzegovina, Serbia including Kosovo, Macedonia, Montenegro and Albania, as well as staff from OXFAM's regional offices.

The conference ran for three days and after the first day in the plenum, we broke off into parallel working groups covering common, "neutral" topics such as the health of women with disabilities, education, social protection and employment, and I put forward a proposal that one of the topics cover the sexuality of women with disabilities. I was supposed to deliver that workshop. In the plenary hall, there were lists on the wall with the names of the workshops, where women signed up for the workshops they were interested in.

There were a lot of names on all the other lists, but only two people had put their name down for the workshop on the sexuality of women with disabilities. During dinner I started coaxing others to put their name down for the workshop, because it seemed that the women were much more interested in

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[59] Marina Blagojević - Hjuson (1958-2020), sociologist, feminist and gender equality expert, scientific advisor at the Institute of Criminological and Sociological Research in Belgrade. (Ed.note)

the topics of healthcare, employment and the like, and that no one was interested in discussing the sexuality of women with disabilities. As I went about convincing the women that this was a particularly important topic, through word of mouth the title of the workshop began to shorten, first becoming just sexuality, and eventually becoming a workshop on sex! As the title of the workshop shortened, so the number of participants increased...! In the end, about fifteen women turned up for the workshop.

While other workshops were attended by women without disabilities and some men, this workshop was restricted to women with disabilities in order to create a “safe” environment, because merely discussing the topic made them uncomfortable. We started off talking about whether they ever thought about their sexuality, whether they talked to anyone about it, how they experience their body and what sexuality means to them.

I remember a girl from Albania who said that this was the first time she’d ever allowed herself to think of herself as a sexual being and that she’d never talked to anyone about it. It was a traumatic, but also liberating experience for her, and a few tears were shed. Her confession was touching and she wrote me a few verses in Albanian the next day as a sign of gratitude for being made aware of her sexuality and for being afforded the opportunity to talk to women like herself about that kind of experience. I kept those verses for a long time, but in the end they got lost in various relocations and paperwork tidy-ups.

By the end of the workshop the women had come out of their shells and allowed themselves to think about themselves as women who are sexual beings with a right to a sex life and family life. I was delighted that we raised this issue but unfortunately it was a one-off forum which has never been replicated in the region since.

Did you work on any other gender equality campaigns?

At the OXFAM office in Belgrade, every new hire also had to complete an induction course, which covered issues of discrimination against women and discrimination against persons with disabilities. I developed a special curriculum on double discrimination against women, which was tailored to disability organisations, as well as staff working at OXFAM and other international humanitarian agencies and organisations. I also noticed an unusual phenomenon: issues of discrimination against women were easier to grasp if we presented them through stories of women with disabilities, probably because disability is much more visible and comprehensible for people when you draw their attention to it rather than the story of discrimination against women in general, because they find it difficult to acknowledge this discrimination even when they recognise it. Ever since then, one of the areas I invested effort in, trying to improve matters, was the issue of women with disabilities. That was another area that I was the first to introduce to Serbia. It seems that I've always been "destined" to break boundaries and push the limits.

It's only now when I think back on my life that I realise the considerable merit of all my achievements during my time at the Yugoslav Muscular Dystrophy Association because I was, in effect, the only woman in the organisation's leadership or at its head, the only woman recipient of two commendations among male activists, and the first woman president of the European Alliance of Muscular Dystrophy Associations - EAMDA. It's funny looking back at photos from that period now, how at all the forums, conferences, various chairing groups, I'm the only woman sitting at the table flanked by men!

I subsequently went about my work always mindful of gender equality, which is one of the specific goals of our Center. I included it in all our projects and participated in various forums where issues of women and gender equality were discussed, always trying to raise awareness of the double discrimination of women with disabilities.

I am especially proud that in 2007 the US Embassy nominated me as the first woman from Serbia for the international "Woman of Courage" award, presented by the United States Government.[60] I didn't receive the award, it was given to brave women from some African countries. However, the fact that to this day I remain the only nominee from Serbia for this award (which of course is not awarded to just women with disabilities) is recognition enough of my work and promoting the issue of women with disabilities.

How did the "...Iz kruga - Srbija" organisation come into being?

I met my colleague Lepojka Čarević-Mitanovski[61] when I started working for OXFAM. At that time, she worked for "Food for Life", which worked with OXFAM. We had at the time just financed a project for a women's group, and I stipulated that at least one woman with a disability should participate in it, and I proposed Lepojka. That's how she came into contact with issues of women and discrimination against them and two years later she founded an organisation called "...Iz kruga" which was the first organisation in Serbia to start dealing specifically with issues of women with disabilities and violence against them. The City gave them office space in the Beograđanka building, where they held various types of workshops hand in hand with organisations that dealt with issues of women or violence against them, such as the Incest Trauma Center. I also participated in their workshops. Later, "...Iz kruga" continued to grow and establish similar organisations in other parts of Serbia, but I no longer played any direct role in it because up until 2001 I worked concurrently at OXFAM and the Center for Independent Living Serbia, which we founded in the

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[60] United States Department of State (Ed.note)

[61] Lepojka Čarević-Mitanovski (1963 – 2015)

meantime. However, through the Center and certain projects, education and research, I continued to deal with gender perspective. I continued to cooperate with “...Iz kruga” down through the years, and Lepojka was one of my closest associates who I could always bank on when it came to furthering the independent living cause.

When was the Center for Independent Living Serbia established? How did it come about?

When I returned from Ireland armed with all the knowledge and experience I gained there, I was eager to establish an organisation in Serbia similar to the Dublin Centre for Independent Living where I had worked. I discussed it with old acquaintances and told them about how I’d worked and functioned there with personal assistants and how it had provided me with the opportunity of a more active and independent life. On the strength of that we agreed on February 6, 1996, to establish an organisation in Serbia called the Center for Independent Living Serbia.

For the Center’s logo we chose the image of a boat (a sailing boat) on the high seas, with the sun in the distance because our logo is an expression of our understanding of independent living, as a voyage on the high seas, which gives freedom, independence and breadth, but is also accompanied by unpredictable storms and perils which we consciously accept. And although it seemed impossible at times, we held fast that no one could stop the idea whose time had come.

As the Center’s “anthem”, we borrowed part of the Irish ballad “Voyage” by singer-songwriter Christy Moore, which I’ve already mentioned, the verses of which go like this:

> “*Life is an ocean and love is a boat*
> *In troubled water that keeps us afloat.*
> *When we started the voyage, there was just me and you.*
> *Now gathered round us, we have our own crew.*
> *Together we’re in this relationship*
> *We built it with care to last the whole trip*
> *Our true destination’s not marked on any charts.*
> *We’re navigating to the shores of the heart”*

They accurately reflect our beginning and path because when we set off, we were headed into the unknown, our journey had never been undertaken in Serbia before. Our destination hadn’t been mapped, we were guided by our desire for the realisation of human rights for people with disabilities based on the social model of disability, the recognition of the abilities of persons with disabilities and the development of our potentials and personalities, promoting the philosophy of independent living and paving the way for its realisation in Serbia.

That was and remains to this day the wording of the Center's core remit: promotion of the philosophy of independent living and paving the way for its realisation in Serbia. The goals we set for ourselves were: advocating for the realisation of the rights of persons with disabilities; promoting a social and holistic model of disability; recognition of the abilities of persons with disabilities, development of their potentials and personalities; trialling and promoting new support services (personal assistance); raising awareness about an accessible environment; work on legislation and advocating for the rights of women with disabilities.

Besides me, the Center's founders were: Mimica Živadinović, Anđelka and Stojan Nastić, Lepojka Čarević-Mitanovski and Slobodan Mitanovski, Damjan Tatić, Borivoje Ljubinković, Aleksandra Haravan, Radomir Stojanović and Branko Rajić. Save for Mimica, the rest of us are people with disabilities. Of all the founders, only three of us remain active today: Damjan, Mimica and I, while Borivoje stood down from all activities a few years ago. Others moved on to other things (Aleksandra and Radomir), Anđelka moved to Croatia, and, sadly, Stojan, Branislav (a.k.a. Pop) and Lepojka are up above navigating other heavenly seas.

How did you meet Damjan and your other colleagues?

I knew Damjan from before because he was in our youth group at the European alliance, at EAMDA. Mimica met him first while I was in Ireland, and while he was still studying we got him involved in the EAMDA youth group. Borivoje was the president of the Cerebral Palsy Association, whom we had worked with during our time at the Muscular Dystrophy Association of Serbia. I knew Stojan, Anđelka and Pop from my Fojnica days, when the first Muscular Dystrophy Association of Yugoslavia was founded, and then they just got involved of their own accord when I came back and told them about my experiences in Ireland.

The Center's registered address was at the still formally existing Muscular Dystrophy Association of Yugoslavia, which for all intents and purposes was completely hamstrung in the absence of working capital. So for the second time in my life I found myself as one of the founders of an organisation that was completely void of working capital, but boasted good will instead. The first funding that the Center received came in the form of a prize from a competition organised by Austrian Airlines to mark its anniversary. The prize consisted of free plane tickets to Vienna for those who wrote the best explanation as to why they should be given the tickets. So, we applied and I wrote an essay about independent living and assistants and how there is a

Center for Independent Living in Vienna. We explained that we would like to go on a study visit to see how the Center operates. When, lo and behold, we got eight free tickets to Vienna! Then we received money from the Ministry of Social Welfare to cover accommodation, food and local transport expenses, and so a small group of activists set off on that study visit because it was important for them to get an idea of what such an organisation was actually doing.

What happened to the Center between 1996 and 2017?

Because we weren't in receipt of specific allocations for our work, I received funds through OXFAM to translate and publish certain information that was not existent, including brochures such as "Removing Barriers to Full Participation", "The Social Model of Disability" and a set of handbooks published by the British organisation Disability Awareness in Action, dealing with managing an organisation, advocacy, campaign management and the like.

We also worked on accessibility issues. From 2001 to 2006, we organised five conferences on accessibility, four of which had an international dimension. In the first year (2001) we organised a conference with assistance from the Ministry of Urban Planning and Construction, and as early as 2002 this conference gained an international dimension and every year it drew a large number of participants and lecturers from the region and the EU, such as Handicap International (which part funded the conference through the SHARE-SEE project)[62], the Council of Europe, the European Disability Forum (EDF) and other professional institutions and organisations. The first conference was entitled "Accessible in the Twenty-First Century", followed by regional conferences "Accessible in the Twenty-First Century - Now!" (2002), "Access is a Human Right" (2003), "Access to the Physical Environment, Information and Communication and Education" (2004) and "Freedom of Movement - An (In)Accessible Right?" (2006). The conferences had between one hundred and one hundred and fifty attendees from seven to thirteen countries. These conferences had a huge impact on raising awareness about the importance of accessibility and contributed to the enactment of new regulations in this area. We managed to amend the Spatial Planning Act, to introduce standards for obstacle-free construction, which had penalty provisions for non-compliance with the standards, albeit for new buildings and those that are being adapted, but in any case we managed to amend that law and introduce mandatory accessibility provisions in some other laws too[63].

I was the head of the organising team and was involved in planning the

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[62] Self-Help, Advocacy, Rights & Equal opportunities in South East Europe – SHARE-SEE (Ed.note)

[63] The Planning and Construction Act, which requires public buildings to be accessible and the Prevention of Discrimination against Persons with Disabilities Act were adopted on 17 April 2006. (Ed.note)

programme, contacting participants from different countries, among which, in addition to disability organisations, included representatives of institutions and lecturers from countries such as Great Britain, France, Italy, Belgium and others.

And when did you start working on promoting and organising personal assistant services?

In early 2001 we received money from OXFAM to organise the first experimental personal assistant service for ten beneficiaries, which lasted three months. The purpose was to give people an idea of what personal assistance means, and at the same time we did a little research as a case study and published it under the title “Personal Assistance as an Alternative Form of Support for the Disabled”. This case study revealed that changes in quality of life cannot be brought about in such a short time frame and that it takes much longer before changes become noticeable, which, of course, required considerably more resources.

We interviewed potential beneficiaries in the Beograđanka building, in the restaurant on the fifth floor, because we didn’t have an office because the office we have now was damaged during the bombing.

People were selected, not because they had the greatest need for this support, but because we felt they had the capacity to further lobby for the creation of conditions for organising a personal assistant service. I learned at OXFAM that if you want to effect change, you have to choose people who will be “champions”, and not those who find themselves in extremely challenging circumstances who would struggle to make an impact, leaving the more “tenacious” among them to effect change and continue to help others.

I myself developed a curriculum for beneficiaries and personal assistants alike, covering topics from the philosophy of independent living, the social model of disability and the principles underpinning the personal assistant service. Due to a lack of funds, we couldn’t fully apply all the principles and make a large selection. We tried to ensure that future beneficiaries had two or three potential personal assistants whom they could talk with, but it wasn’t easy, because future beneficiaries didn’t have the requisite knowledge or skills to assess their needs and select the appropriate assistant and manage the service.

Also, starting in 2001, I developed a curriculum for workshops that I’d previously delivered through OXFAM, adding the topic “Philosophy of independent living of people with disabilities”, which was attended by today’s leaders of local organisations from different cities.

In order to have our own team that would also work on raising awareness of the philosophy of independent living, in 2001, also with the help of OXFAM, I organised the first Training of Trainers (ToT) for which we selected a group of people among whom were Svetislav Marjanović, Dimitrije

Gligorijević, Vojislav Mladenović[64], Duško Savić and Miroslav Marjanović[65], who underwent this training on how to hold workshops on raising awareness of people with disabilities and the philosophy of independent living. That first ToT ran for four days and we held it in Obrenovac, hiring trainers who had already passed OXFAM's training for trainers. We worked all day learning how to present certain topics, design workshops, relationships with participants and the like, and after dinner the participants had a work assignment to devise part of the programme for such a workshop. We had an associate who then recorded the presentations made by the participants and played them back, and together we discussed what was good and what could have been better. In order to maintain concentration levels, we occasionally, during breaks, handed out sweets and chocolates to the participants. The training was exhausting and years after that, our friend Vojče from Smederevo said that that training was worse than the bombing, and that since then, every time he sees sweets and chocolates his stomach turns. Regardless of that, he was one of the best trainers in our small team and it's a great pity that he passed away a few years ago.

We held trainings not only for the benefit of our organisations, but also for Handicap International, which established "Living Upright" centres in several cities in Serbia[66]. We also delivered workshops for the UNICEF team in charge of creative day habilitation programmes. It was through this medium that members of our Education Team "cut their teeth" because I held the first workshops with my friend Lola, who had a clear grasp through keeping company with me about what it means to be a person with a disability. I remember we held workshops all over the place. Once in Kragujevac in Šumarice, there was no hall available, so we held the workshop in the park, and posted the papers from the flip charts to the surrounding trees.

We worked a lot with the media. Television guest appearances, conversations, negotiations, and we used that time to advocate and establish local centers.

How were the local centres established?

After those trainings, we started visiting different cities in Serbia, the hometowns of our trainers, to hold workshops and promote the idea of independent living to pique the interest of as many people as possible in this cause.

It was against that background that local centres for independent living began to appear slowly. The first was established in Niš, and then in Leskovac, Jagodina and Smederevo. Later, we established centres in Sombor, Kragujevac,

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[64] Vojislav Mladenović (1957-2013) (Ed.note)

[65] They later launched and managed or are still managing centers for independent living in Leskovac, Jagodina, Smederevo and Niš.

[66] Up. footnote 36. (Ed.note)

Bor and Čačak. We also established a local organisation in Belgrade in 2010, where, of course, the seat of the Center for Independent Living Serbia remains.

How did the SPAS[67] project come about?

The Personal Assistants Service in Serbia (SPAS) project was a follow-on to publication of a case study that we did as a trial personal assistants service and thanks to the support and assistance of Mrs. Ann Pešić, Honorary Consul of the Republic of Ireland in Belgrade. I made her acquaintance during my time at OXFAM as she worked for UNICEF and we'd met at meetings of foreign humanitarian agencies that mainly dealt with the issue of refugees from Croatia and Bosnia and Herzegovina. She's from Dublin by the way, and while at UNICEF she heard about a certain Gordana Rajkov from Belgrade who had worked in Ireland and was heavily involved in the disability movement in Ireland. She relayed how she'd heard a lot of nice things about me, how I helped educate people there about independent living, how I protested with them outside Dáil Éireann, how I had a phone line installed in a house where two young men with disabilities were supposed to move into, etc.

At that time, the Irish International aid agency "Irish Aid" was examining the possibility of doing something in Serbia, and thanks to Ann Pešić, I met with their delegation and their ambassador who was stationed in Budapest but also covered Serbia.

I met the ambassador in my apartment (because I didn't have transport or someone to assist me to get to the meeting), so Ann came with the ambassador for tea and cake and I talked about my experience in Ireland, the case study we'd conducted and said that I'd like us to transfer the example of good practice from Ireland to Serbia and organise a personal assistant service. It sounded very tempting to the Irish because a project of that kind could also effect change in the social protection system. They decided to fund one such project that was to run for several years. And with us being a small local organisation, it was recommended that we apply together with a large organisation owing to the large sum of funding (six hundred thousand euros over three years), which they weren't sure we could manage adequately. In addition to the Irish government, the project was funded by the American organisation Catholic Relief Services (CRS), which applied for the project, the Ministry of Social Affairs, and the beneficiaries through their co-payments, which was mandatory from the outset.

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[67] Abbreviation of Service of Personal Assistance in Serbia – SPAS. The word "SPAS" means also "salvation" in the Serbian language, and it was really salvation for the people who used the service (Ed. note).

In the first cycle, the Irish government covered only the net amount?

It was the same in both cycles because the donors didn't want to pay taxes in Serbia from donations collected from the people of Ireland. I went to the Ministry for negotiations with Ljiljana Lučić[68] and with Gordana Matković[69] to arrange for the Ministry to provide us with the money to cover the taxes, which at the end of the day never passed through our hands because the state paid out the money and returned it to itself. That's how the Ministry financed that part of the costs.

We'd already participated in the poverty reduction program implemented by CRS and we knew Sanja Nikolin[70] and I recall inviting Sanja for a chat and we ended up fleshing out ideas for a joint project in my living room. Sanja was delighted with the idea and saw to it that CRS applied for the project, with us listed as "contractors", that is, for us to roll out the service on the ground. So they applied for the project, which the Irish government agreed to fund, and which consisted of three segments: one was to roll out the service on the ground, the second was to conduct research into changes in beneficiary quality of life and prepare a cost benefit analysis, and the third was advocating amendments to the Social Protection Act to make provision for the service within the system. It was a very extensive and important project. We assembled a large project team: I was project manager, my colleague Mladen Jaramaz oversaw communication with potential personal assistants, and Gorjana Gordić was in charge of communication with potential service beneficiaries. Borivoje Ljubinković oversaw research, Jovanka Andrejević was in charge of education, and we also hired an administrative and financial assistant. There were five other local project assistants in cities where the project was rolled out. CRS handled overall financial management for the project, and Mimica Živadinović, who was working at CRS at that time, was assigned the role of liaison officer, i.e. for liaising between CRS and the Center. We had to go through rigorous checks and procedures for bookkeeping, reporting, spending, and a whole lot more.

What about the cost-benefit analysis on personal assistant services?

We engaged the Institute for Economic and Social Research to conduct the cost-benefit analysis, which was prepared by Dr. Mirosinka Dinkić and Jelena Momčilović. This analysis was supposed to show whether it was possible and beneficial to roll out a service of that kind in Serbia. Information

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[68] Secretary for Social and Child Protection in the City Administration of Belgrade (2006) and State Secretary at the Ministry of Labour and Social Policy 2008-2011. (Ed.note)

[69] Minister of Labour and Social Policy 2000-2004. (Ed.note)

[70] At that time, Sanja Nikolin was the executive director of the Belgrade office of CRS. (Ed.note)

was collected from institutions (there was only one residential care facility catering for persons with physical disabilities), so they were compared with information on assistance costs, and against gross domestic product, and the conclusion was that the costs do not differ substantially, that they are almost on a par with the cost of the service in residential care facilities. The research conducted by Dr. Mirosinka Dinkić confirmed that the costs are not substantially higher but instead even the same 51% : 49%, but that the quality of life is vastly better when you have personal assistance rather than when you are placed in an institution.

And what about research into changes in quality of life?

At the same time, we conducted participatory action research, which was supposed to show changes in the quality of life of personal assistant service beneficiaries. This research was conducted by a 16-member research team, headed by Sanja Nikolin and Jasmina Kijevčanin, with each the team member having special responsibilities. All beneficiaries and assistants participated to a certain extent in the research and their experiences were used to conduct the research. Both pieces of research were published, one under the title “The Price of Independence” and the other under the title “Experiences of Independence” and are available in the e-library on the website of the Center for Independent Living Serbia[71].

How did the project move forward?

The project started in 2002 with preparatory work (development of

Some of the SPAS project beneficiaries and personal assistants, Belgrade, 2005

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[71] [illegible] and http://www.cilsrbija.org/ebib/200712121938330.PAR_english.pdf (Ed.note)

procedures, training of beneficiaries and assistants and selection of assistants), while the service itself commenced in August 2003. During the three-year project cycle, seventy people with disabilities started using the personal assistant service in five cities[72] across Serbia.

All service beneficiaries went through a tailor-made training program that aimed to empower beneficiaries and equip them with the skills and know-how to manage the service. The training for SPAS beneficiaries covered seven topics, including models of disability, the philosophy of independent living, self-assessment of one's needs, conducting interviews and communication, and so on, and the training employed simulations of different situations, case studies and the like. Personal assistants were given training that covered models of disability, the philosophy of independent living, principles of the service, and so on.

To put some form of safeguards in place for beneficiaries, all personal assistant candidates underwent personality testing at the National Employment Service, and prior to which they completed specially developed questionnaires in order to collect general information about them. Beneficiaries also completed specially developed questionnaires in which they set down their needs, the gender of the assistant they needed, what skills they should have and what age the assistant should be. Also, beneficiaries were required to keep diaries about their experience using the service, what they did, what changed for the better and what for the worse. These diaries were used in the participatory action research. We regularly held meetings with each other, visited cities throughout Serbia where the service was in operation and monitored the development of the entire process. Project assistants in each of the cities were in constant communication with beneficiaries and assistants and also monitored the service. And that's how, in fact, the service began. So the service, and of course the entire independent living movement in Serbia, which served as the basis for the personal assistant service, gave people an entirely new lease of life that they'd never experienced before and the chance to change the quality of their lives. It was, in fact, the discovery of a whole new world. These experiences were crucial because they motivated people with disabilities who were service beneficiaries to start advocating and campaigning the service to be included in the system because they'd experienced major changes in their lives. It's simply not possible to fight for something you've never experienced before.

It's worth mentioning that at the outset people didn't know how to assess their own needs, nor how much assistance they needed time-wise, but they began to understand their own needs through the experience of using the service and learned to explain to the assistants how to help them best, and in doing so, they practically educated their assistants themselves.

We made a documentary about the experiences from this project called

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[72] Belgrade, Leskovac, Jagodina, Smederevo and Sombor (Ed.note)

"The Idea Whose Time Has Come" which can be found with English subtitles on YouTube.[73]After completion of the SPAS project, none of the service beneficiaries returned to the life they led pre-project, and they tried various avenues to secure assistants for themselves. I also remember an assistant in Leskovac who worked for Goca's[74] sister who had no income whatsoever, save for disability-related financial support (Caritas had provided funds for an outdoor stairlift), agreed to pay the co-payment for Gordana Stojanović's sister from her salary just so that she could continue to have a personal assistant.

Service beneficiaries and personal assistants at one of the training sessions in Jagodina, 2005

We couldn't violate the co-payment principle because once you violate it then there will always be fresh arguments to waive it in another case. We, i.e. the Center, also drafted new projects through which we attempted to securing funding for this service.

The Center had a bird's eye view into the circumstances of at least a hundred people who have used the service so far, what did you find?

People completely changed their outlook on life. They had new ambitions, they were motivated to do something, to get involved in something, to continue their education, to start their own families. For example, Šaponjić, who was a service beneficiary, otherwise a wheelchair user, married a girl who also had a disability, and then they decided to move out from their family homes, were given an apartment by the municipality and lived together with the

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[73] https://www.youtube.com/watch?v=FRLaYMbwC7I (Ed.note)

[74] Gordana Stojanović, President of the Muscular Dystrophy Association in Leskovac, President of Center for Independent Living Leskovac from 2008 to 2014 (Ed.note)

support of a female personal assistant and one male assistant. Our colleague Sveta from Leskovac, who hadn’t left his house in twenty years, and was cared for by his elderly parents, suddenly got the opportunity to function independently and be able to do something thanks to the personal assistant service. He founded the Center for Independent Living in Leskovac, which he still runs today, and a few years ago he founded his own printing house: he became an entrepreneur! He built a small modern printing house in the yard of his house, and so now he takes care of his mother, who is still alive, instead of expecting the help of others. At one time, he was also a member of the Leskovac Municipal Assembly Council in charge of social issues and was for all intents and purposes involved in politics.

Dimitrije also made major changes in his life. He founded the Center in Jagodina, which he still runs today. He decided to move away from his village, sell his field, and took out a loan and bought an apartment in Jagodina. When that apartment was finished, he moved there to live with the help of an assistant and the support of people he hires additionally. He became a completely different man and he now takes care of his old and frail mother. Both Sveta and Dimitrije are members of our Training Team, and Dimitrije is a coach for accredited training for personal assistants. It’s a job that he still does today, travelling widely to deliver those training courses.

How did Moma[75] end up at the Center?

At OXFAM I designed and led a project called “Disability Studies”, which ran from January to May 2002 and was implemented in Smederevo and Belgrade, with nineteen people with disabilities involved. The goal of these studies was skills acquisition in negotiation, advocacy and lobbying for the rights of persons with disabilities. We put an ad in the newspaper, and people with disabilities applied, whom we interviewed, and then we chose project participants. Moma was one of the people who came to interview. I’d met him previously at Trade Union Hall (Dom sindikata) at an exhibition to celebrate December 3[76]. He came up to me and said: - Well, I wanted to meet you because I heard you on television and it was one of the rare occasions that I heard someone with something intelligent to say. By the by, he was seething about the situation at the time, he even took it on himself to write letters to various institutions demanding reform. I jokingly called him an “angry man” because he was absolutely livid about the situation at the time.

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[75] Momčilo Stanojević (Ed.note)

[76] International Day of Persons with Disabilities. It has been observed since 1993 by way of a UN resolution. On December 3, 1982, the World Programme of Action Concerning Disabled Persons was adopted. (Ed.note)

Another of our disability studies course participants was Paja[77]. As the course had a high training session content, including a communication training session, he constantly struggled with the notion of “assertiveness” because as a former soldier he was accustomed to direct orders and discharging duties.

Another key independent living movement activist, our colleague Gorjana Gordić[78], is a product of that disability studies course.

For the project’s practical module, the participants decided to prepare a publication about accessible public facilities in Belgrade entitled “White Dots”. Its promotion was held at the Faculty of Architecture in Belgrade as part of a campaign for an accessible environment. Gorjana was later the author of two more editions of “White Dots”, which looked at the accessibility of cultural and public institutions. Both Moma and Gorjana were beneficiaries and participants in the SPAS project.

There are many more examples of people who have changed their lives, and part of their stories can be found in our research paper “Experiences of Independence” and the documentary that I’ve already mentioned. They were all changes that none of them could have imagined thirteen years ago until the SPAS project began.

Everything we delivered through this project: developing procedures, standards and rules for organising personal assistant services, we did it pretty much completely under our own steam, lifting the lid on a new area of action which had been a complete unknown in Serbia. We had no examples or models in Serbia to guide us through this process and we relied solely on the experience that I and, to an extent, Mimica gained while working in Ireland. So, you can see that the model for providing personal assistant services has its roots in the Irish experience, albeit adjusted to the conditions in Serbia and thus became a specific model for Serbia. We also chronicled our experiences in the cost-benefit study, authored by Borivoje Ljubinković and myself, and which was recognised and registered as copyrighted work in the Intellectual Property Office of Serbia in 2007.

What did advocacy to include personal assistant services in the system entail?

At the same time, at the political level, we began to advocate legislative amendments, inclusion of the service in the system, and state funding. The project ran for the best part of four years, during which time the reins of power in Serbia changed hands three times. This meant we had to constantly start over and brief each government and new minister about the value of the service and what it means for beneficiaries and the state.

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[77] Mihailo Pajević, President of the Association of Paraplegics and Quadriplegics of Serbia (Ed.note)

[78] President of the Talos Belgrade organisation (Ed.note)

In 2008, work started on the Social Protection Act, which was underpinned by new principles and drew on a set of social protection services, standards for which were being developed with the support of Oxford Policy Management (OPM). This team assisted the Ministry in developing minimum standards for certain services, among which, unfortunately, there was no personal assistant service. At the same time, our Center received funding from the Social Innovation Fund for the “From Innovation to Standardisation” project. We turned to the British working with the OPM team to help us develop standards for the PA service using the same methodology used to develop the standards for the Ministry. Indeed, an OPM team expert agreed to work with us voluntarily to develop these standards. So when the standards for the seven services being developed by the Ministry were finished, we also had standards for the PA service at the ready, which were even more comprehensive than the others because we’d taken account of European standards and the one from Ireland. In the end, the Ministry accepted our standards, which were later included in the official Rulebook on Minimum Standards for the Provision of Social Protection Services.

I was a member of the working group for drafting the Act. It was during this time that I realised just how challenging the job is because priority setting is fraught with difficulties. I’d advocate for a service for people with disabilities and then I’d have to clarify the difference between children deprived of parental care or some other vulnerable group. The concept was to “localise” all community services. Concurrently, the grassroots worked on lobbying, on creating campaigns for the introduction of personal assistant services.

The entire process of enacting the law that was passed in 2011 and the Rulebook on minimum standards of 2013 took about five years. During that time we tried to maintain a “skeleton” service so that people could continue to access it and continue to advocate and campaign for it. The activists in Sombor were the first to manage to secure funding from the local authorities for a smaller number of PA beneficiaries, followed by our activists in Leskovac, Jagodina and Smederevo. Lamentably, as late as last year, the City of Belgrade had yet to provide funding for the service. Only on 5 May 2015, on European Independent Living Day, did we manage to get a promise of funding for this service in Belgrade. In July 2016, funding for fifty service beneficiaries was allocated by the Secretariat for Social Protection of the City of Belgrade.

There were misunderstandings surrounding the purpose of the personal assistant service, whether it should be accessible to both children and persons with intellectual disabilities. Negotiations were very intense and in the end we succeeded in having the standards for the PA service included in the Rulebook just as we had developed them, with a helping hand from UNICEF, which at that time was committed to supporting families and children and introducing a personal companion service for children.

You mentioned that in Ireland this service was left to the Irish Wheelchair Users Association (IWA). We've not yet adopted that component of interest alignment on a basis that is unrelated to diagnosis. That's part of the problem.

That's the stage we're at now. Why would I organise a service in Kragujevac, in Leskovac, in Jagodina, when we have our own organisations there. They need to argue for it. They've also learned how it's done and what the procedures are, meaning the Center for Independent Living Serbia no longer needs to primarily deal with organising the services, except maybe for a while longer in Belgrade. Our role remained advocacy, policy, legislation, strategy, the introduction of international standards. I somehow have the feeling that I've fulfilled my mission, that is, that the Center has done its main job in terms of organising the personal assistant service, and that it's now up to our local organisations to develop it going forward.

What did the gender structure of personal assistant service beneficiaries look like then and how does it look now?

I think it was always somewhere close to fifty-fifty. There were no significant differences between men and women. We always tried to have a balanced gender structure, although it didn't hinge so much on us as on the people who needed and applied for the personal assistance service. Prioritising girls or women with disabilities over men was simply out of the question if the needs of the men who applied for the service far outweighed and were far more justified. The gender structure is also contingent on the type of disability, because, for example, among people with physical disabilities, most have spinal injuries, while multiple sclerosis mostly affects women.

The gender structure of the SPAS project was 57% men and 43% women, which confirms what I've just said because among the SPAS beneficiaries 42% were people with spinal injuries. The gender structure of the Belgrade service, which was rolled out in August 2016, is 54% men and 46% women. I think that this ratio, bearing in mind all the determinants, is satisfactory.

And what personal benefit did you derive from the SPAS project?

I feel somehow much richer for the experience because with the help of a number of associates I managed to bring this great idea, which was just in its infancy, from far-flung Ireland to Serbia, to breathe life into it, and now a huge "army of people", two hundred and fifty, live that idea every day .

As for the quality of my life there was no drastic change because I'd lived alone before, while it was possible, and then I lived an independent life the best I could manage. For the 2001 pilot project I wasn't even a beneficiary because in my mind other people needed it more in order to get a feel for independent living for themselves. I only became a personal assistant beneficiary when the SPAS project came on stream and of course it made my life much easier, especially considering that I have muscular dystrophy and that my physical abilities are waning with age, which means I now require physical assistance from another person. Of course, the personal assistant service, regardless of the significant deterioration of my physical condition, has allowed me to remain active in the disability movement, to travel, work, deliver training seminars, workshops and much more besides.

What is the Center's relationship with the European Network on Independent Living (ENIL)?

The European Network on Independent Living was founded at a conference on personal assistance in Strasbourg in 1989, which brought together over eighty people with different types of disabilities from over twenty European countries. It gave rise to the inaugural Constitution which set out ENIL's mission of building and coordinating organisations for independent living in Europe, thereby establishing the European Network on Independent Living - ENIL. ENIL was established to address issues of underrepresentation of persons with severe disabilities, that is, those who require daily assistance in going about their everyday life, underrepresentation in politics as well as in disabled persons' organisations.

ENIL, led by Adolf Ratzka, initially functioned as an informal network, a facet that Bente Skansgard[79] from Norway insisted on vehemently. Later, when the number of member organisations increased, ENIL adopted its first official Constitution and registered as an organisation in Ireland, where its Secretariat was located.

I'd heard about ENIL before I left for Ireland and I also met many ENIL activists from different countries face to face in Ireland at the symposium which I helped to organise, which I've already discussed.

When we founded the Center for Independent Living Serbia, we applied for and gained membership of ENIL, and since I was already involved in various ENIL activities, I was appointed as a member of the ENIL Board (Executive Board) which in practical terms ran the organisation.

I was a member of the ENIL Board until 2011, at which time I decided to resign from the Board, and we put you forward as our representative on the Board. I then became a member of ENIL's Advisory Board, which already included Adolf, John Evans and several other veterans of the movement, so it seemed to me like the "Council of Sages", and we left it to the younger ones to manage the organisation going forward.

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[79] Bente Skansgård, founder of the independent living movement in Norway, who passed away in 2013, was president of ULOBA, Norwegian Independent Living organisation, currently the most influential independent living cooperative in Europe. (Ed.note)

I remain of the opinion that ENIL has a somewhat unusual Constitution, whereby a member can be an individual and/or an organisation from a country and that everyone has one vote in the Assembly consisting of these individuals and one representative from each organisation from the different countries. I suggested that this be changed because I think it's quite absurd for a member organisation with hundreds of members to have the same decision-making right as an individual member coming from that same country and yet represent completely contrasting views.

There were other ENIL workings that I found strange, like the fact that leading organisational roles were scattered across Europe: the director based in Sweden, the co-director in Dublin, the head of information in England, the head of projects in Germany. I always found that to be slightly awkward in terms of coordination, but the others insisted on a loose organisational structure unlike other classic European organisations.

How was the Freedom Drive campaign launched?

Participants from Serbia and Bosnia and Herzegovina at Freedom Drive 2011

The Freedom Drive was Martin's brainchild and is organised every other year in Strasbourg, home to the European Parliament (but also the Council of Europe), bringing together activists from as many European countries as possible. This event usually had a working conference, followed by a march through the streets of Strasbourg from an agreed meeting point to the European Parliament building where an ENIL manifesto containing requests to the European Parliament would be handed over and a meeting would usually take place in the Parliament building attended by all event participants and MEPs who wanted to take part.

One improvement that ought to be made in connection with this event is that, when the curtain comes down, there needs to be a mechanism in place for adopting specific working conclusions about what steps are to be taken going forward, the realisation and success of which would be discussed at the next Freedom Drive, something which is lacking at this point in time. I'm not sure that we have a clear and measurable indication as to whether we've succeeded in driving major change on the back of this event from its inception in 2003 to the present day, except that we may have garnered a greater number of participants from different countries to take up ENIL's cause. In the beginning, while Adolf, John Evans and Martin were there, all true legends of the movement, there was a vision of what was to be achieved and it made sense. But they grew weary and stepped down, replaced by a new cadre with different outlooks and ideas. Younger members have joined and that is undeniably good for the future of the organisation, but I'm slightly troubled by the relocation of ENIL's headquarters to Brussels, which is far from ideal because it is home to "three million" various organisations resulting in ENIL "getting lost" in the crowd. It would make more sense if we had a Secretariat in Brussels for the sake of greater leverage because it is home to the European Commission and the centre of funding decisions. But moving the entire Freedom Drive event from Strasbourg to Brussels wasn't a sound decision for various reasons - logistics and increased costs to name a few - and because we've moved away from the Council of Europe in Strasbourg. I feel that this event no longer reflects the independent living movement as it did before.

Of course, our Center remains an active ENIL member, so, for example, in 2011, as part of ENIL's activities, we organised a regional conference in Belgrade for the Balkan countries.

And in 2013, ENIL established the Hall of Fame and inducted pioneers of the independent living movement in Europe who have significantly contributed to its development. I am honoured to be one of the inductees of the Hall of Fame, alongside Adolf, John Evans, and Martin.

And how did the "Step toward Europe"[80] regional conferences held in Sarajevo come about?

The first "Step towards Europe" conference was held as part of the "Advocacy and Leadership" project, which we delivered in partnership with IC "Lotos" from Tuzla and the CRS office in Bosnia and Herzegovina, and also funded by the Irish agency for international development "Irish Aid". This regional project began in September 2003 and ran until April 2005. Through a programme of education and practical work, it involved thirty-two persons with disabilities from fifteen organisations of persons with disabilities from Serbia and both entities of Bosnia and Herzegovina. We held four "mixed" workshops where people from Bosnia and Serbia participated together. It also served as a new experience because for many of the participants it was their first time visiting another country since the end of the armed conflicts and they were initially apprehensive about how they would be received by people from other former Yugoslav republics.

Initially, that project didn't include plans for the conference. The idea originated one day in my living room (Let me tell you, my living room has welcomed many a guest and played host to a litany of ideas...). Sanja and Suvad

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[80] Conferences were held in 2005 and 2008. (Ed.note)

from Lotos and I discussed various issues and then the idea came to us that the European Union accession negotiations could be used to further the issues of persons with disabilities and measures to improve their situation in our countries and harmonise them with European standards. I immediately sat down at the computer and the three of us outlined what the goal of the conference would be, who should be invited, who could finance it and so on. Afterwards, Suvad lobbied the CRS Office in Bosnia and Herzegovina to organise the conference as part of the "Advocacy and Leadership" project, and funding, in addition to that given by Irish Aid, was also provided by Handicap International through the SHARE-SEE project.

The 2005 "Step towards Europe" conference was attended by over one hundred and fifty participants, including persons with disabilities and government officials from countries in the region, as well as representatives of the European Disability Forum, the Council of Europe, and the chair of the European Commission's Interparliamentary Group on Persons with Disabilities.

Mixed delegation from Serbia at the "Step towards Europe" conference, 2005 in Sarajevo

The highlight of the conference was the participation of leading legendary activists for the rights of persons with disabilities in Europe, such as Adolf Ratzka from Sweden, John Evans from Great Britain, Kalle Könkkölä[81]

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[81] Kalle Könkkölä (1950-2018), politician, independent living and human rights activist from Finland. See more: http://enil.eu/news/the-world-became-my-room-kalle-konkkola/ (Ed.note).

from Finland, Giampiero Griffo[82] from Italy and Dónal Toolan[83] from Ireland. The conference discussed for the first time the setting down of specific conditions in the field of disability to be included as an integral part of the general conditions for accession to the European Union by countries in Southeast Europe. At the end of the conference, a Resolution was adopted containing the goals we’d set ourselves for the next two years, and in 2008, also in Sarajevo, a second conference was held under the same name “Step towards Europe II”, where progress in respect of the Resolution’s goals was summarised.

Those meetings had their comic moments too. After such a big event it was standard practice for the SHARE-SEE project steering committee to meet and review the event, what worked well and what could be improved. First to speak were the project partners from Macedonia, followed by the Association of Students with Disabilities, who wished, first and foremost, to thank the organisers for a conference well-organised, and then came our turn to speak. My colleague Borivoje opened with the words: - ‟And I would also like, first and foremost, to thank the organisers...” Of course I nearly collapsed and said: - ‟For the love of Jesus, Borivoje, we are the organisers!” - but he didn’t take a blind bit of notice and just ploughed ahead: - ‟the one thing I would say is that the conference occasionally got out of hand because of the constant stream of new material.” Now it was Suvad that was stupefied because they’d gone to great lengths to immediately copy all the keynote presentations and make them available to the participants.

That event has gone down in history at the Center. At forums organised by our Center, my colleague Damjan has a habit of opening his presentations with the words: - ‟In a time-honoured tradition here at the Center, I would like, first and foremost, to thank the organisers...” If everyone suddenly starts talking aloud at workshops or training sessions, I usually interject with: - ‟It seems that this event is getting out of hand...” Those utterances have stood the test of time as an insider joke between those of us that go back that far, and it always gives us a good laugh.

You mentioned that, among other things, this conference was funded by Handicap International?

Those years from 2002 to 2006 were action-packed. It was during that period that we rolled out three large-scale projects in parallel - two regional and one in Serbia. I managed all these projects more or less, of course, in partnership and with the immense help of steadfast associates: Mimica, Moma,

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[82] Giampiero Griffo, President of Disabled Peoples’ International Europe (DPI Europe) (Ed.note).

[83] Dónal Toolan (1966-2017), activist for the rights of persons with disabilities and inclusion, journalist and actor from Ireland (Ed.note).

Borivoje, Gorjana, Mladen and our frontline associates: Sveta, Vojče, Dule, Dimitrije and Julijana.

In 2002, together with CRS, we received funding for the SPAS project (the roll out of which began in August 2003), and in early 2003 we started work on the SHARE-SEE project which ran until 2008 with funding from numerous donors.

The goal was to empower disabled persons' organisations (DPOs) and promote the regional movement of persons with disabilities in South East Europe (SEE). The project was implemented in partnership by Handicap International, the Center for Independent Living Serbia, the Association of Students with Disabilities from Serbia, the Information Centre "Lotos" from Tuzla, Bosnia and Herzegovina and Polio Plus from Macedonia.

It consisted of several segments, including the development of human rights training materials, the exchange of information on anti-discrimination policy, what provisions exist in national legislation, and current related advocacy initiatives in the region. Trainings were organised for trainers who came from different countries, and then they held a further twenty training sessions for other disabled persons' organisations. This was coupled with ongoing advocacy at the national level for the adoption and implementation of an anti-discrimination legal framework using international instruments. As part of the SHARE-SEE project, we also organised national conferences in Serbia, Bosnia and Macedonia called "Unified Voice", which aimed to bring together disabled persons' organisations and encourage them to collaborate on goals that they themselves set.

A special segment of the project was the award of small grants to organisations from countries that participated in the programme, by way of an annual competition, where organisations applied for small-scale projects that they would like to implement, employing the knowledge acquired during the training. These projects were evaluated by partner organisations that ran the programme (Handicap International, Lotos, Center for Independent Living Serbia and Polio Plus). We evaluated projects from Albania, Macedonia and Bosnia, Lotos evaluated projects from Serbia, Kosovo and Macedonia, and so on, and the points were then added up, with the final selection made based on the average.

In its five-year existence, the SHARE-SEE project has contributed to further empowering the disability movement in the region and changing attitudes to disability by adopting an approach based on human rights and the social model.

You mentioned EDF as an organisation at the European level. Who reached out to it and how was the National Organisation established?

The European Disability Forum (EDF) is an independent European non-governmental organisation (ENGO) that represents the interests and advocates the rights of 50 million people with disabilities in the European Union. It was founded in 1996 and is headquartered in Brussels. EDF has four membership categories, including organisations from EU Member States, which are full members, with non-EU countries given observer membership.

We've been collaborating with EDF since 2004 because they provided support for the "Step towards Europe" conference as part of the lobbying and advocacy project run by IC Lotos from Tuzla, the Center for Independent Living Serbia and the CRS office in Bosnia and Herzegovina.

In mid-2005, EDF implemented the CARDS programme[84],one of the goals of which was to promote closer relations and regional cooperation between EU countries and candidate countries in Central Europe, which included Croatia, Bosnia and Herzegovina, Serbia (including Kosovo), Montenegro, Macedonia and Albania.

Given that we'd reached out to them and collaborated during the "Step towards Europe" conference, EDF asked our Center to take on the role of coordinator of the EDF - CARDS project for Serbia. The project had three main strategic goals: a) to form national organisations of persons with disabilities in these countries and b) to prepare a report on the position of persons with disabilities in each of these countries (working to an agreed methodology) and c) to adopt a national strategy to enhance the position of and policy towards persons with disabilities in each of the countries.

The programme ran for two years. The Center for Independent Living Serbia formed a Working Group to draft the Report on the Situation of Persons with Disabilities in Serbia - An Analysis of Legislation and Practice, led by Damjan Tatić, with representatives of all national associations of persons with disabilities in Serbia partaking in the process. The report was printed and published in 2007 and can be found on the Center's website[85].

As for the formation of an umbrella organisation, for years Serbia had a so-called coordination committee of organisations of persons with disabilities, which was a network of organisations that collaborated on issues of common interest. Thus, the foundations were already in place for an umbrella organisation of persons with disabilities in Serbia, and the Center assisted in its formal establishment and drafting its Constitution. So, in June 2007 it was established as a legal entity called the National Organization of Persons with

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[84] CARDS - Community Assistance for Reconstruction, Development and Stabilisation (Ed.note)

[85] http://www.cilsrbija.org/ebib/200707251933330.Izvestaj%20-%20srpski.pdf (Ed.note)

Disabilities of Serbia (NOOIS).

That project gave birth to the first National Strategy to Enhance the Position of Persons with Disabilities for the period 2007-2015.

What were the membership criteria for an alliance or network of organisations to join the National Organization?

Full membership in NOOIS was open to organisations that:

- drew their membership from or represented the majority or the largest number of persons with certain types of disabilities or were organisations that brought together persons with various forms of a disability to address specific issues
- had at least five hundred regular members, persons with disabilities other than organisations that drew their membership and represented persons with very rare disabilities (such as Rett syndrome)
- had a network of at least five local and regional organisations
- operated throughout the Republic of Serbia or a substantial part of it
- had been established and operating for at least five years

Unlike most EDF members and umbrella organisations in other countries, which are structured along the medical model and whose members are organisations that bring together people with the same type of disability, the so-called “classical” organisations, such as organisations for persons that are blind and partially sighted, deaf and hard of hearing, persons with paraplegia and quadriplegia, persons with cerebral palsy, muscular dystrophy, persons with intellectual disabilities, etc., membership in Serbia is also open to organisations that bring together persons with various forms of disability to address specific issues (such as independent living, the rights of women with disabilities, etc.). NOOIS is an observer member of the EDF.

And what status does the organisation “...Iz Kruga” hold?

“...Iz Kruga” is an associate member of NOOIS given that it still does not meet the criterion of having a network of at least five local organisations. I still think that NOOIS membership criteria should not just be quantitative in nature (membership numbers, years in operation, etc.), without any consideration of qualitative criteria that can be used to gauge the results achieved by an organisation, the changes it has effected, its sphere of operation and so on.

The Center set in motion the drafting of the first shadow report on the implementation of the International Convention on the Rights of Persons with Disabilities. What is involved in this process?

Serbia ratified the United Nations Convention on the Rights of Persons with Disabilities in 2009 and, accordingly, is required to report every two years to the United Nations Committee on the Rights of Persons with Disabilities about the situation in Serbia and the compatibility of Serbian legislation with the provisions of the Convention. Serbia's initial Convention implementation report was made in 2012, but it was only in 2016 that it came up for consideration before the UN Committee.

As early as 2009, and prior to the drafting of the National Report for Serbia, the Center worked on a project entitled "Capacity Building of PwD Organisations for Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities", supported by the European Commission's EIDHR programme[86], which had two main goals - building the capacities of disabled persons' organisations to monitor implementation of the Convention and to organise educational activities for disabled persons' organisations on how to prepare a Civil Society Shadow Report and prepare the first draft of the report.

When the country report on the implementation of the Convention was published, on our initiative and in partnership with the NOOIS and the Center for Society Orientation we prepared a Shadow Report as against the Report submitted by the state. The aim was to comment on the assertions made by the state in its report and to give an accurate coalface picture of the situation because the state placed a heavy focus on the regulations and legislation it had enacted, while our primary focus was on how those regulations function on the ground and whether they really bring about changes in the quality of life of persons with disabilities.

Gordana and Ivanka Jovanović at the presentation of the Shadow Report on the Implementation of the UN Convention, Geneva, 2016

We did all that on an entirely voluntary basis, in the sense that we didn't get paid for it, but we did it with the utmost professionalism. Approaching it as we did we couldn't review every article of the UN Convention (there are 35 in total), but we managed to review 16 articles, including: Article 5 - Discrimination, Article 6 - Women with disabilities, Article 9 - Accessibility, Article 19 - Living

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[86] EIDHR - European Instrument for Democracy and Human Rights (Ed. note)

independently and being included in the community, Article 24 - Education, Article 27 - Work and employment, Article 28 - Adequate standard of living and social protection, Article 29 - Participation in political and personal life. There was no misinformation in the Country Report, but some the information was incomplete. For example, concerning responses to natural disasters and disasters, six different laws were cited, of which only one explicitly mentioned persons with disabilities. The rest were general laws that never made any mention of vulnerable groups. We also pointed out the multiple discrimination of women with disabilities and the amendments required, for example, to the Criminal Code, the Family Code, etc. We pointed out that problems remain with inclusive education, inclusion of children in the regular educational process. With regard to social protection and life in the community, we specifically addressed the issue of deinstitutionalisation and, of course, community life support services, including personal assistant services.

In April 2016, my colleague Ivanka Jovanović and I presented our Shadow Report and attended the presentation of the official Report of the State of Serbia, whose delegation was led by Ms. Suzana Paunović, Director of the Office for Human and Minority Rights of the Government of the Republic of Serbia. We also provided additional commentary that was included in the Concluding Observations and Recommendations of the UN Committee for the State of Serbia. On that occasion, we also met with Mr. László Lovászy[87], where we had the opportunity to highlight issues that the Committee should concern itself with.

The discussion about the systemic discrimination of women with disabilities in the Criminal Code was also interesting, an issue that was fortunately addressed through amendments to the Criminal Code in December 2016.

For me, the experience in Geneva was invaluable, because if I look back just ten years ago to 2006 when we worked with Handicap International on the SHARE-SEE project, the only document we could cite at the time were the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities: there was no other document. Ten years later, not only had the UN Convention been adopted and Serbian legislation harmonised with it, but here we were sitting in Geneva, together with the state, reporting to a United Nations body about the degree of respect in Serbia for the human rights of persons with disabilities. It was a positive that Serbia as a state had left a strong impression, that it had been demonstrated that there is an extremely active disability movement monitoring implementation of the UN Convention, one capable of bringing constructive suggestions for improvement in that field to the table. Significant progress has been made, but there are still problems to be addressed.

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[87] Dr. László Gábor Lovászy, UN Committee member, Rapporteur for Serbia and Adviser at the European Parliament (Ed.note)

Did Lepojka have a hand in writing the section of the Report that deals with women?

She did indeed! Lepojka made a significant contribution to the text of the Report, especially regarding, of course, the matter of women with disabilities, but also issues of access to justice and healthcare.

The Center for Independent Living and the National Organization are involved in a project that should contribute to strengthening capacity for political participation. What progress has been made?

Back in 2012 we implemented a similar idea to promote the political participation of persons with disabilities when working on the project "Together for the Political and Economic Empowerment of Persons with Disabilities" in partnership with NOOIS, supported by the European Commission's EIDHR programme and the US agency National Democratic Institute - NDI[88]. Another of its objectives was to try to establish a parliamentary working group for people with disabilities that would specifically address these issues, and for us to work with the group to pass new or amend existing legislation. The second part of the project was to work at the grassroots level to strengthen the capacity of small organisations and facilitate cooperation with local authorities in three cities: Prijepolje, Novi Pazar and Kladovo. The project was a huge success, we managed to form a Parliamentary Working Group for Persons with Disabilities, amend eleven laws, and in these three cities, memoranda of cooperation were concluded between local authorities and organisations of persons with disabilities.

Cue the 2012 parliamentary elections, which spelt the end of the Parliamentary Working Group for Persons with Disabilities, especially because some of the political parties that supported the group's work (DSS, LDP and the United Regions) failed to win seats in parliament.

However, we continued to look for an opportunity to continue this type of work and submitted a new project to the United States Agency for International Development (USAID) in 2014, with the new project having an added component: influence the electoral process and improve the accessibility of the electoral process for persons with disabilities. We were the project planners and responsibility for the entire project rested with us, in particular regarding dealings with the Parliament, the formation of the Parliamentary Working Group, and legislative amendments. We started the project in partnership with the NOOIS and the Center for Social Orientation, which later withdrew from the project. We continued to work at grassroots level and added two more cities from underdeveloped areas (Bor and Negotin), and NOOIS

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[88] The National Democratic Institute (NDI) (Ed.note)

oversaw activity at grassroots level because their members have a network of local organisations. USAID approved the project in 2015, which began in September and ran for eighteen months, until the end of March 2017.

The results so far are very encouraging, especially bearing in mind that during these eighteen months the National Parliament did not sit for nine of them due to the fresh elections that were held in April 2016.

Nevertheless, we managed to develop well-established contacts with the National Parliament. The official launch of the project[89] was held on 22 December 2015, with addresses given by Ms. Maja Gojković, Speaker of the National Parliament, Michael Kirby, the then US Ambassador to Serbia, Brankica Janković, the Equality Protection Commissioner, and myself as project director. As early as January, the Speaker of the Parliament adopted a decision to form a Parliamentary Working Group for the Empowerment of Persons with Disabilities in Politics, who was also its chair, and which included representatives from both sides of the political divide, and which set to work with enthusiasm. At our suggestion, Maja Gojković put the Prevention of Discrimination against Persons with Disabilities Amendment Bill on the agenda of the last session in 2015.

That was the only item on the agenda and what ensued was a three-and-a-half-hour discussion on the issues of persons with disabilities, with all parliamentary parties reaching consensus that these issues need to be addressed. Never before in the National Parliament had so much floor time been given to the matters of persons with disabilities. However, the debate not only touched on the introduction of autotype stamps, but also on all other issues such as accessibility, the election process, support services and personal assistants. I think it’s a huge step in the right direction, but unfortunately people aren’t aware of it unless they can see tangible changes in their daily lives.

Regrettably, work on this was again interrupted due the Parliament’s winter recess, followed by new elections being called for April 2016.

What is the status of the Working Group now?

After the election and the convening of the new Parliament we managed to re-form the group in October 2016, and its chair is Dr. Vesna Rakonjac, while members include MPs from all sides of the political divide. The group managed to prepare a draft of its work plan and, at our suggestion, in a little over two months, to amend the Criminal Code and amend the Housing Act in line with the needs of persons with disabilities.

I think that my work in the National Parliament significantly contributed to these results being as successful as possible, regardless of the circumstances that were beyond our control. I developed an excellent rapport with a number of MPs, who I believe will advocate measures to improve the position of persons

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[89] https://youtu.be/cbVmBrtdVks (Ed.note)

with disabilities now and in the future when the project is completed, even if those MPs are not returned to Parliament.

What are the project's other achievements?

To streamline efforts to achieve the project's second goal, i.e. increasing accessibility to the electoral process for persons with disabilities, in December 2015 we established the Electoral Reform Group as part of the project, which includes representatives of interested PwD organisations and other civil society organisations dealing with electoral reform issues, such as CESID, Serbia on the Move, etc. As part of the group and the project, we prepared proposals for the Republic Election Commission (REC) for the elections in April 2016, a guide to accessible campaigning for political parties and marketing agencies and an election participation guide for persons with disabilities[90]. Some of the proposals were accepted by the REC and were included in the REC's instructions and explanatory notes and concerned voting by persons with disabilities, the use of autotype stamps and going to the polling station with the help of a guide dog.

Given that the elections cut short our work in the National Parliament, NOOIS, with the support of the Center, signed protocols on cooperation with seven political parties before the elections.

A study visit to the UK Parliament and the UK Electoral Commission proved especially beneficial on account of the exchange of experiences with and learnings from the All-Party Parliamentary Group for Disability of the UK Parliament, which has been in existence for over thirty years.

Regarding grassroots work, several meetings were held with organisations of persons with disabilities and local authority representatives, as well as seven capacity-building trainings for organisations of persons with disabilities with regard to advocacy work in five cities in Serbia. Three action plans have been developed to improve the position of persons with disabilities in Kladovo, Prijepolje and Novi Pazar, where we assisted organisations with signing memoranda of cooperation as part of an earlier project. In Novi Pazar, for example, this Action Plan is the first strategic document adopted to date that concerns persons with disabilities, while proposals for memoranda of cooperation in Bor and Negotin have been drafted.

These results will serve as a sound foundation for the disability movement going forward. I'm convinced that the work of the Parliamentary Working Group for the Empowerment of Persons with Disabilities in Politics will continue, and one of the tasks of the Group will be to analyse the

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[90] These documents can be found in the e-library on the Center's website: http://cilsrbija.org/ebib/201612231013400.cil-unapredjenje_izbornih_prava_osoba_sa_invaliditetom.pdf and http://cilsrbija.org/ebib/201704010956560.vodic.pdf (Ed.note)

recommendations handed down by the UN Committee, some of which should find their way into the workings of the Group, while some should be put forward to various ministries, i.e. the Government, for consideration and with a view to changing current policies.

PART IV
INVOLVEMENT IN POLITICS

What did your experience as a member of parliament (MP) mean to you?

I got into politics without any party affiliation. It was never an ambition of mine to become an MP. It was by pure coincidence that the G17 Plus party asked me to come on board, because their election campaign at the time ran with the slogan "Expertise before politics". So, on the party's list for the 2007 parliamentary elections there were several people who were not party members but were prominent experts in certain fields, such as film director Srđan Dragojević. At that time, I had dealings with Vesna Piperski Tucakov, who was Deputy Minister of Social Protection, and with Ms. Mirosinka Dinkić, who worked at the Institute for Social and Economic Research and had worked on the feasibility study concerning the introduction of the personal assistant service into the system.

G17 Plus, having come up with the idea that persons with disabilities should be included in their political programme, because they lacked a social component, and seeing as no parties had such people on their lists, Mr. Dinkić (I'm assuming at the suggestion of Ms. Tucakov and Ms. Dinkić who knew me as a disability movement activist) invited me for an interview. He asked if I'd accept to be on their electoral list, which having given it some consideration I agreed to, albeit on the proviso that I didn't have to join the party because I'd never held any party affiliation. I'm of the opinion that if someone decides to be a disability movement activist then he/she must be prepared to work with everyone in order to fight for the rights of persons with disabilities. It's utterly irrelevant who is in power or what my opinion is of their politics, political programme, or attitudes. When someone is appointed Minister for Social Policy you've no choice, you have to work with that person. I was taken aback and slightly baffled by the invitation, and I remember that in addition to my colleagues at the Center, I also sought the counsel of Mihailo Pajević and Vesna Petrović[91]. I was keenly aware that this move would notch up political points for G17 Plus, but I was also conscious of the fact that it would give us, persons with disabilities, a platform to raise our visibility and for me to draw attention to the issues of persons with disabilities. Each side had their own interest in this.

They suggested that I participate in the electoral campaign as much as I could, and that's where I "clinched my first victory". These election rallies were held in sports halls and other large venues, where stages were set up for candidates to deliver campaign speeches. I refused to be carried onto the stage, insisting that a ramp be set up so that I could wheel myself up, which they did.

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[91] Vesna Petrović, President of the Republic Association for Assistance of Persons with Autism

They made a large wooden ramp which they transported from one city to another, where election rallies had already been held.

It was an entirely new and somewhat daunting experience for me: you entered a hall to this charged atmosphere: music, flags, slogans, clamour; a setting that was totally alien to me. And when an event got under way I would be first to take the stage first, followed by all the other candidates! I think audiences were absolutely stunned by that spectacle, but it conveyed a new, hitherto completely unprecedented image and message. At subsequent election rallies I also managed to hire sign language interpreters, who stood on the stage next to the speakers and interpreted the speeches.

Gordana at one of the G17 Plus election conventions in 2007 when the stage access ramp was used for the first time at the election conventions of all political parties

During our first conversation, Mr. Dinkić promised me that if his party won at least ten seats in Parliament that I would be among those ten MPs. Everyone said he would renege on his promise, but he kept it nevertheless. So yet again I found myself in a new, completely unknown environment. That said, for me it was “breaking new ground” and winning freedom because I was the first person with a severe disability to be elected an MP in Serbia’s parliamentary history. I held this office for two terms, from 2007 to 2012.

Why did I get involved in politics? Because I believe that even if you want nothing to do with politics, politics is guaranteed to find its way into your life, through legislation and measures that affect how you live your life. It happens with or without us, and we’d certainly be better off playing a part in it.

In fact, it was only then I realised that since 1966 I'd always been involved in politics, when we founded the Muscular Dystrophy Association of Yugoslavia, although I wasn't aware of it nor did I give it much thought. All our work, everything we do on behalf of organisations of persons with disabilities to put forward proposals and seek new solutions, constitutes political action. To do so doesn't require party membership or office in a state body.

What surprised me when I started working as an MP is that other MPs and parliamentary clerks, regardless of their political affiliations, addressed me with great respect, which is not the case in everyday life. The work, however, was not without its difficulties. While serving as an MP I encountered many obstacles, from the inaccessibility of the halls for plenary and other sessions, the rostrum from which the MPs deliver their addresses, the toilets, the restaurant...There was also zero recognition of the need for any additional assistance or allocation of funds to hire a personal assistant.

It caught the media's attention: the first person with a disability elected to Parliament. They came to film me being carried down the stairs to the plenary hall, but a mobile wheelchair platform was set up there very quickly. When Parliament sessions were moved to the House of the National Parliament, ramps were built in both the Grand Hall and the Small Hall and an accessible toilet installed to make the building as accessible as possible**.**

Gordana's maiden address in the plenum of the National Parliament of the Republic of Serbia in 2007

The first time I took to the rostrum came as a bolt from the blue. There was a meeting of the parliamentary party because the budget was being debated (which, of course, I still had no clue about), when Mr. Dinkić said: Gordana, it would be welcome if you could say a few words about the funds that are set aside for the employment of persons with disabilities. I had to quickly think of something to say about it and take a look at another budget line concerning funds to support organisations of persons with disabilities. I jotted down a few main points (because, of course, speaking time in Parliament is very limited), and when I returned to the hall a technician came up to me and said: - "We'll bring you down a microphone, so you can speak from your seat", because I was sitting in the back row. I said: - "I'm not speaking from here. Nobody delivers an address from their seat, everyone speaks from the rostrum. I'd kindly ask that you mount a microphone next to the rostrum because I can't physically stand at the rostrum." Apart from the piece of paper containing the few points I'd jotted down, I conjured up my keynote opening lines as I made my way through the hall to the microphone. As I took to the rostrum, I was struck by stage fright because addressing Parliament in front of MPs is worlds apart from the conferences where I'd spoken without hesitation. And then, for the first time, absolute silence fell over the hall, there were no comings and goings, no heckling, nobody reading the newspaper. Everyone sat and listened intently, probably astonished to see me there despite seeing me in the corridors every day. You could have heard a pin drop in the hall. My parliamentary party colleague, Mr. Nikola Novaković, who was deputy speaker of the Parliament, often said: - "The only time when Parliament resembled Parliament was when Goca[92] spoke." The only shame was that this atmosphere had more to do with their astonishment at seeing a person with a disability deliver an address than it did with its content. I opened my maiden address to Parliament with the following words:

Mister Deputy Speaker of the National Parliament, Honourable Ladies and Gentlemen, Members of Parliament,

In my maiden address to this House, I would like to start by expressing my delight that one person with a severe disability has finally been afforded the chance to participate, on an equal footing, in the work of the highest legislative body in the country. Of course, that does not diminish, rather it only adds to my trepidation about the challenges that obviously await me in office, but it is my hope that I am merely the harbinger and that more people with disabilities will have this opportunity in the next term.[93]

I could never have been an MP without a personal assistant. In fact, the work in Parliament called for at least two assistants, sometimes more than twelve hours a day. So, I made an application for and the Parliament approved funds to hire one assistant, while the Center provided the second assistant through projects. Sometimes not even that was enough, so my friends Mimica or Desa would join me because I couldn't remain on my own, and sessions would sometimes wrap up at one or two in the morning.

It was a real eye-opener for the Parliament and MPs as it gave them a grasp of what it takes for an MP with a serious disability to function and work. I succeeded in have the Standing Orders of the National Parliament amended,

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[92] Gordana's nickname

[93] The entire address is available at: https://youtu.be/Aad6pgl3IX4. (Ed.note)

which now include an article that stipulates that a Member with a disability is entitled to assistance in line with their individual needs, funds for which are to be provided by the National Parliament, including the hiring of personal assistants. The greatest value and satisfaction I got was in the changes in the quality of life and the fact that I revealed and opened a new world to some people.

During my term in office I came to realise how complicated the law-making process is: from the ministries that prepare preliminary drafts, bills, to obtaining consents from other ministries, primarily the Ministry of Finance. Only when Government adopts a bill is it sent forward to Parliament for debate in principle, and then in detail when amendments are submitted, and finally the law, as amended, is adopted in its entirety.

I learned how to word amendments, what specific form they should take, when you can submit them. My amendments passed eighty percent of the time because in the meantime I would lobby for them in the ministries that were submitting the law, sometimes they even helped me draft an amendment to ensure it had the best chance of being accepted. In addition, I often consulted with the NOOIS about the amendments and took their proposals on board, which gave the amendments real significance, e.g. to make something accessible, to improve healthcare, social protection, and so on. There was a lot of work to be done in that regard. There was a lot of material to peruse and very little time to study everything and give constructive suggestions. I learned a lot, but I also worked a lot - it was a full-time job. Especially those two terms in office, because the ruling majority was very narrow, one hundred and twenty-seven deputies, while the quorum was at least one hundred and twenty-six for a vote to be valid. I attended the sessions every day because Belgrade-based deputies were expected to attend. Physically it was very, very strenuous.

During my second term in office I wanted to pack it in because it was both physically and mentally too stressful for me. Mr. Dinkić, however, submitted that my presence had been a watershed in the history of parliament, and that it would be a shame if I resigned from office. He also suggested some respite. They stayed true to their word and during my second term in office I didn’t have to attend all the debates, but I had to be present for voting, which used to last for six or seven hours because of the numerous amendments.

You once told me that some of the home care staff and other colleagues could not fathom your political engagement?

Well, that’s no surprise. Envy is human nature. What made less sense was that even the disability movement had a hard time understanding my position. Some speculated that they had chosen me and delegated me there. There were various theories. For example, that I was only in it for myself, receiving an MP’s salary, pushing my own agenda, without giving a damn about persons with disabilities. If two hundred and forty-nine deputies receive a salary, why should I, as a person with a disability, forego it? I was appointed on my own merit because certain people felt I was up to the task and could do the job. The reputation I earned while working in Parliament was based on my activities and work. I was on good terms with everyone, I was courteous to one and all. So, there was no reason for anyone to feel uneasy in my presence, as is usually the case when you are from another political party. Last year, when the NOOIS requested an audience with the President of the Republic at that time, Tomislav Nikolić, I was also a member of the delegation. I met him several times, even when I was no longer an MP, and he always addressed me as a colleague. On that occasion, he said: - ‟Despite us being on opposite sides of the House, when Gordana was in Parliament everything seemed so much more cordial. When she was present, deputies watched their language.” The trading of insults was commonplace in Parliament. That’s something I was never on the receiving end of.

What were the benefits of your work as an MP?

Working in Parliament was a golden opportunity to raise awareness about persons with disabilities. The very fact that they met me as a wheelchair user in the corridors and halls every day, and that I was “there in front of them” every day, it became the norm for them to encounter persons with disabilities in various settings. There are people who follow parliamentary debates on TV and then when they see you in the hall as a wheelchair user they realise that persons with disabilities are not incompetent, that they are capable and have a voice. People change their tune towards persons with disabilities when they hear you delivering addresses about and discussing matters of a relatively scholarly nature and unrelated to any party-political debate. I think that awareness levels have changed a lot and that there have been profound changes in public perception of the abilities of persons with disabilities.

In this regard, I remember one anecdote, which illustrates the different view of us as persons with disabilities. I was in town and stopped at the “Kolarac” café to use the toilet, because, unfortunately, there is not a single accessible public toilet in Belgrade, save for those in shopping centres. There was a lady seated at the entrance to the toilet charging a fee for use of the toilet. I went to leave money, but she persistently refused to take it and said sympathetically: - ‟No, you don’t have to.” So, I don’t have to pay because I’m a person with a disability, which in a sense implies that I’m a luckless, lesser being. In the end, I somehow managed to leave the money, use the facilities, and as I was leaving two other women were waiting outside and one of them said elatedly: - ‟Goodness gracious, it’s our MP!” Who knows what, if any, her politics were, but she saw me as an MP, as one of the ordinary folk who actually advocated human rights. It was quite a comical situation in which on the one hand I'm viewed as a "poor incompetent soul", and on the other as a respected individual, as an MP. That's one example of how through my role as an MP, a greater media presence on television and at public political events, the visibility of persons with disabilities has been enhanced. Through my influence on legislation, I had a hand in further integrating disability in public policies. Access to state institutions (physical, informational and communication) has also improved, and I think that taken as a whole this has led to some political parties rethinking their manifestos to further involve persons with disabilities. Last but not least, my work as an MP has encouraged and motivated other persons with disabilities to engage socially and politically in their local communities.

What challenges come with the job?

Well, it's never plain sailing. If you're a member of a political party and you take up office in a state body such as the National Parliament, you're generally required to, above all, represent the interests of your political party, which are not always necessarily aligned with those of the disability movement. However, the upside is that, usually, fellow MPs and decision-makers don't measure your performance in the light of your disability, rather by your personal qualities and the contribution you can make. The downside is that in many places there is still zero awareness of the need to level the playing field through providing conditions and ensuring specific support to allow you perform your duties, which ultimately again suggests that common stereotypes and attitudes towards disability remain.

Nowadays persons with disabilities are either running as candidates for councillor or are otherwise politically active in many local authorities. That is one of the impacts of the 2007 elections. A lot changed that year?

Indeed! As I mentioned, awareness and perception around persons with disabilities has shifted, as has their drive to immerse themselves in political processes, especially at grassroots level. I think that my tenures as an MP and the results I achieved really left a mark. That said, I think it's worth adding that the choice of person with a disability to be appointed to a certain position does matter. It's really not something to be taken lightly. It would be important to have persons with disabilities, and I've no hesitation in saying this, people like myself, who are smart, who know what they are doing and go about their work with dignity, and who are not politically bitter. Otherwise, the message about persons with disabilities that you want to send to others gets lost.

What is your take on the current state of the movement?

I think the movement is losing traction. The outlook is grim. I'm afraid we are on a tack towards the medical model again, which is disappointing. All enthusiasm has been lost. Bar a few exceptions, people in local organisations have reverted in large numbers to activities such as art colonies, sporting competitions (which of course is not a bad thing and here of course I'm not referring to top athletes and Paralympians), various creative workshops, handicrafts and the like. That would all be fine if they were complemented by some other advocacy activities. Organisations that are actually engaged in advocacy, that cooperate with local authorities and provide the best possible living conditions for persons with disabilities are thin on the ground. The main topic is how much money an organisation will receive for so-called programme activities.

The level of collaboration is nowhere near where it needs to be, there are numerous organisations with different points of view and ways of operating, which are often at odds with one another, intolerance among organisations is rife, proving counterproductive, while zeal to do something for the common good is waning. Exceptions to this are few and far between, not to mention volunteer work. Fewer young people want to get involved in organisations, which is a general problem globally, commonly referred to as the "benefit trap". The more conditions persons with disabilities have that allow them to lead a normal life and work, the less incentive to get involved in organisations of persons with disabilities. This will pose a major problem in the future because when the older generations are gone, there will be no one to "keep an eye on the situation" and continue efforts to maintain and build on the inroads made to date into the living and working conditions for persons with disabilities.

As far as individuals, persons with disabilities are concerned, many have fallen into the trap of sitting at home glued to a screen and criticising the efforts of others. Without having the first clue about those matters. Without ever having lifted a finger in their lives. There is greater enthusiasm among some people who are not persons with disabilities, who are eager and want to do something to improve the position of persons with disabilities, than persons with disabilities want to do for themselves. And that, I think, is the elephant in the room. Persons with disabilities fail to see that they need do something for themselves, not to wait for someone else to do it for them. And that most of the rights they now enjoy were but a pipe dream thirty years ago and that someone fought for those rights, and that you now enjoy rights and privileges that someone else once fought for.

To give you an example, when the Parliamentary group was established in January 2016, we posted the news on our website and Facebook page, while there is also a video on the Serbian Parliament's YouTube channel. A gentleman from Loznica who is the president of an organisation of persons with disabilities wrote to me and said: - "The setting up of this Group is all grand and dandy but what good will I get out of it? My position hasn't changed at all. I'd ask that the deputies from the Working Group brief me, but only on weekdays, between ten thirty and eleven o'clock about my participation in political life." How do you respond to that? Neither was it lost on me the pointlessness of my cordial letter to him to explain that his organisation can also address this Working Group and put forward suggestions about what should be improved, and how everything that his organisation does and the changes it proposes in their local community is in itself political participation. You'd be waiting in vain from ten thirty to eleven o'clock for someone to brief you about what you participated in if you haven't a clue yourself and never participated in it.

A message to those currently in the movement and those who will take up its mantle.

If we fail to attract fresh-faced youth and activists to the ranks, I'm not sure what direction the movement will take going forward. I'd like the movement to grow stronger and evolve into a genuine force and an interlocutor on an equal footing with authorities in Serbia so that we can really see to it that "nothing about us happens without us". When we started out, it was an era of youth, enthusiasm, and poverty. Today we are no longer so poor, but there is a fall-off in enthusiasm, although it seems that enthusiasm is inextricably linked to and engendered by poverty and the absence of any rights.

I remember one sentence by Goca Čomić[94] at a gathering dedicated to women, when she asked those present whether we knew what we were standing on that day. The answers were varied: the ground, the floor, high heels; only for her to say: - "You're standing on the shoulders of all those women who fought before you to be where you are now. And if you don't get involved, the next generation won't have any shoulders to lean on, to drive the cause further, they'll only find themselves going in reverse."

This message, which was put across to the women, is actually relevant to both the disability movement and persons with disabilities. It would do no harm for everyone to occasionally remember that they are "standing on the shoulders" of those who toiled before them to create the conditions and rights they enjoy today. They should continue to spearhead the movement so that those new-comers have "shoulders" to stand and fight on. The only solution is to get everyone involved.

Finally, I would like to encourage persons with disabilities to fight for a better quality of life, because there are two choices: to do nothing, just sit around feeling sorry for yourself like some "poor defenceless creature" whom the state couldn't care less about, lambasting everything, making no effort or to

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[94] Gordana Čomić, Member of Parliament on behalf of the Democratic Party (Ed.note)

give yourself a shake and do something for yourself. Even if you don’t succeed, you’ll be back to square one, but not at a loss. That should not be viewed as failure. Because the only real failure is to do nothing. As soon as you try to change something, you’ve already achieved something. As we know, rights don’t come on a platter nor should they be subject to arbitrary withdrawal, instead they should be championed and a vigilance maintained to preserve the inroads that have been made to date. Benefits gained can be easily lost, as is now the case in many European countries, and we should remain vigilant to ensure that this does not happen in Serbia as well.

What is your take on the current position of women in Serbia?

I think the position of women has changed over the years. It seems to me, at least from the stories I heard and my vague memories, that immediately after the Second World War women were held in high esteem, considered equal and often moved in the upper echelons of political life. I think that even back then women were not aware of gender roles and that despite that equality, they were expected to continue to fulfil their gender socially determined roles. I’d be at a loss to explain how it is that this somewhat equal standing has changed and deteriorated over the years, but it’s a fact that women were blatantly discriminated against twenty years ago. I think that the situation is changing for the better, aided by the fact that nowadays there is a growing recognition of and increasing dialogue around this discrimination. The political view is that women are equal and there is legislation to that effect. A lingering problem is that legislation is not always adequately formulated, compliance with the current Gender Equality Act is inconsistent, with a new one in the pipeline, but people’s prejudices are difficult to change and a good number of women remain oblivious to the discrimination against them.

The situation is improving, there are more and more women in public and political life in high political office and senior managerial positions, but that is still not enough. The Serbian Parliament passed a law stipulating that at least one third of the deputies on political party lists must be women, and that was somehow adhered to. However, as soon as the Government was formed this ratio was slashed and yet again the vast majority of ministers are men. Furthermore, the classic division into men’s and women’s jobs hasn’t vanished, so a woman, despite being the successful director of a company, still has to take care of the house and children on her own, and that is work that is neither recognised nor valued. On top of all that is the grave problem of domestic violence against women. The number of women who lose their lives every year at the hands of their spouses or partners is worrying and it appears to be on the rise. Women from otherwise marginalised groups, such as Roma women, and women with disabilities, are in a precarious position because they suffer multiple discrimination.

And what is your message to women?

If by that you mean women in general, I’m not sure that I’m the right person to put across such messages, since it’s not my area of expertise. But when it comes to women with disabilities then I think first and foremost that as many of us as possible need to wake up to the discrimination we face based on our gender, as well as our assigned and expected social roles, which a large number of women with disabilities cannot fulfil as is expected of them precisely because of their disability. It’s difficult to recognise that someone is discriminating against you just because or only because you are a woman, and only then because you’re a woman with a disability. I think we should try to understand that we are entitled to influence our lives, which, of course, is not easy, especially if you depend on other people due to a disability because there is no adequate support in the community. Women with disabilities most often see themselves as less valued, less capable, and rarely allow themselves to even think that they are worthy of someone’s attention and love as women. By virtue of that, they often perceive abuse and violence by their partners as a kind of “love” and sign that someone might love them too. Much work needs to be done to raise awareness of discrimination against women in general, and women with disabilities in particular, and to adopt measures to prevent that discrimination. Until recently, some laws even systematically discriminated against women with disabilities. Efforts should also be made to involve women with disabilities in women’s rights organisations so that both the disability and women’s movements can accord recognition to the specific situation in which we as women with disabilities find ourselves and work to improve our position. However, to do so would require us to get organised, to put forward a united front and start viewing ourselves as capable, dignified and beautiful, because only if we believe in that ourselves will others see us that way.

Given that you’ve been involved in social processes for half a century, how do you view the role of the individual in the development of the state and how would you like to see this country and the region in the future vis-à-vis the current state of play?

Only individuals can change the system. That’s always been the case. All movements started with individuals. Neither the women’s movement nor the black rights movement (I don’t think this phrase is pejorative) started out with five hundred or a thousand supporters all at once. The women’s suffrage movement was started by a handful of people, starting with Susan B. Anthony to Rosa Luxemburg, as well as the civil rights movement and Rosa Parks, who was called the mother of the freedom movement, and Martin Luther King and a couple of confidants. The same can be said of the disability movement spearheaded by Ed Roberts, Justin Dart Jr., Judith Humman. Change starts with individuals, with a small group of astute and dedicated people, who know what they want, have a vision of their own, advocate that vision and try to motivate as many people as possible to row in behind that idea. Not all people concerned will get involved, but the event itself, the knowledge - the understanding that by doing so, you are having an impact on hundreds of other people and their lives, whether they are aware of it or not, means in fact that it is having an impact on and changing the system.

I would like both Serbia and the entire region to collaborate, help one another, and respect the integrity and social and cultural differences of others, which rather than put them at cross-purposes will serve as a robust platform for better understanding. I would like to see Serbia as a community with an organised system of functioning, rule of law and a defined value system that guarantees social equality in terms of opportunities for the development and enjoyment of fundamental human rights by every citizen of this country, regardless of differences, a society that values knowledge and competence while sustaining optimism, and encouraging citizens to get involved and take responsibility.

I'm aware that this sounds like an idealised view of the world, but without it we would wither and lack motivation and ideas on how to move forward. It takes courage and tremendous optimism (if not lunacy) for a person, against a background of poverty, unemployment, and an exodus of young people from the country, to get involved in a movement for change, and this is especially true for persons with disabilities.

And if you don't get involved, you end up...

Then you end up with, for example, the current UK scenario, with rights being restricted and reduced, only to have to kick start the entire process all over again just to get back to where you left off instead of making gains. In today's world where money is king, people are merely interested in how they can secure funding and material benefits, and there is no other approach. And the "best" method is to arouse some pity and have people do something for you out of pity. I don't want pity. I want continuance, I want respect, I want to maintain my dignity. And it's not always about the money, rather about ideas, the moment, organisation, the good will of people who want to do something about it. It is important to have sound laws even if they're not enforced in full, and sometimes not at all. I'm an ardent supporter of law making, although everyone says its codswallop. Laws may be flouted or not applied, but then you have a mechanism in place and say: - ‟Law enacted, take it and apply it." In the absence of that, then you don't have any argument and it hinges on whether Tom or Dick comes to power, one of whom is sympathetic to the cause, the other who isn't. All that requires dogged persistence, a broad outlook, and a yearning to keep learning. I’ve been working in the movement for fifty years and I’m constantly learning something new. I enjoy going to seminars and workshops where you get to hear fresh ideas, which help you to further improve your work.

PART V

JUBILEES ON THE PERSONAL AND WORK FRONT: Twenty years of development of the Center and movement for independent living in Serbia

Before we discuss marking the twentieth anniversary of the development of the Center for Independent Living Serbia, I would like to take you back to another event from 2004, your sixtieth birthday party.

Yes, but that was a very private event, which was in no way related to anniversaries celebrating the Center's life. The idea behind it was probably prompted by a childhood memory from my mother's funeral. Recalling those post-funeral scenes, when friends and family of the deceased congregate at the funeral and then chat about what's been happening in their lives since the last time they saw each other, and completely forget about the person they came to pay their last respects to. So, I'd imagined getting all my friends together while I'm still alive to throw a party. Then when I leave, whoever turns up, turns up, and let them talk about what they want. I was tormented when I sat down to put the guest list together because there were over a hundred people on the list that I know from different periods of my life. In the end, I just about managed to cut the guest list down to eighty. Of course, I alone paid for my diamond jubilee birthday party. I decided to hold it in the Hotel Yugoslavia, where we'd often organised various seminars and events, and which has a large conference room and an accessible toilet. Several of my friends offered to help with the planning, so Desa did the seating plan for the tables, making sure that people who knew each other from different periods or circumstances throughout my life were seated together. My friend Ljilja took care of the decorations. She bought scores of purple and pink balloons which she hung around the place, and some purple beads and candles which were arranged on the tables. Lola hired the "Strings" street ensemble, which plys its trade in "Skadarlija", Belgrade's Bohemian quart. And at some point, as a surprise, Mimica hired and paid for, as her gift, a traditional trumpet ensemble from Vlasotince! When the musicians made their entrance to the rhythm of the south, trumpets blaring, the initial reaction was one of stunned silence, followed by sheer delight. Moma got out of his wheelchair, Borivoje danced a version of "Shota"[95] and Desa followed his lead. The best part was that everyone I invited from Belgrade and further afield turned up, like Sveta from Leskovac, Dule and Vojče from Smederevo, Dimitrija from Jagodina, Suvad even came from Tuzla, and of course my brother Saša from Germany.

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[95] Shota is a dance that was very popular throughout the former SFRY, which in its present form comes from folklore choreography (Ed. Note)

The party kicked off around six in the evening and lasted until the small hours of the morning. I offered to put up those who had travelled from afar in the hotel, out of my own pocket, but they declined, and when the curtain came down on the “shindig”, they hopped in their cars and drove home.

Gordana with her brother Saša at her sixtieth birthday party in 2004

What also made the party great was that guests who knew each other were seated at the same tables, so at one table were a handful of my relatives and associates from the office, at other tables were either people I hung out with way back when or from my time working at the Muscular Dystrophy Association of Yugoslavia, then my personal friends, with all the people I met while working at the Center seated at two tables. By doing the rounds from one table to another, I was able to take a “take a stroll” down memory lane. I sat together with my brother, Mimica, Luka, Suvad, and some of my long-time assistants and Ann Pešić from Ireland.

And since my birthday was on December 29, the hotel was decked out in decoration, with a Christmas tree standing outside, lending a festive air to the occasion, and at some point, there was a fireworks display. Suvad gave a speech, the atmosphere was great, everyone said that they couldn’t remember the last time they’d experienced such joy and jubilation. My brother came armed with a camera, which he used to film snippets of the party. Using that entirely amateur material, our associate, film director Jelena Đokić, who worked on the SPAS film, made a half-hour film called “Goca’s Milestone Birthday”. I’m thrilled that it was taped so I can always play it back and see people from different periods of my life all gathered under the one roof to celebrate my birthday, not so much because of the birthday, but as an occasion to celebrate, because of the unique chance of having everyone together in the one spot. So that was the moment when I tried to take a trip down memory lane in one day, and bring together people I’d worked with, met and mixed with at different stages of my life, some of whom I still rub shoulders with, and they got a chance to meet each other. This video is even more valuable now because in the meantime some people have departed this world for the next and are no longer with us in person.

Can you just tell me what your relationship was like with your brother and did he have a family of his own?

He left for Germany about fifty years ago. He visited Belgrade occasionally, and we spoke often over the phone and on Skype. He lived with his German wife Ingrid for almost forty years, but they had no children. In recent years, he has found it more difficult to get around and he tires easily when walking, so he hasn't been to Belgrade in the last four years.

In a strange way, he didn't want to accept the situation that I find myself in with my illness. The flipside of that was that he had understanding for all others in a similar position. I guess he perceived me as someone who can do anything and he didn't accept the fact that my life is not easy either, which is a shame. I wish I'd had a brother who I could have relied on more, with a family of his own. A wife, children...to have nephews and nieces. They'd probably have children of their own now and I'd have close family. I reckon that he'd have wanted that too, but, alas, it didn't turn out like that - I guess that's what life had planned.

You marked the twenty-year anniversary of the Center for Independent Living?

Yes, last year, 2016, we marked and celebrated twenty years of our work. Like our logo, this celebration was dedicated to our ship's voyage, with the projects signifying the ports we visited where we were joined by new crew members each time. And you find something new in every project. So, for example, in the disability studies, the new seafarers were: Moma, Gorjana, Dule, Vojče, Paja who took up the full weight of this cause. And then on to some other seas, international cooperation, taking the cause to the region: Bosnia and Herzegovina, Croatia, Macedonia, Albania, and Montenegro, where we ran workshops on the philosophy of independent living, which gave wings to the cause, and spread this idea around.

What were its key achievements?

We've always believed in our independent living cause, we believed it could become a reality - and it has. Our initial motto "The idea whose time has come" has become "The idea that is still flowing..."

We are bound by ideas about the exercise of human rights of persons with disabilities, their social recognition, a commitment to the idea of freedom and independent living, a desire for new knowledge and a way of working that necessitates the active involvement of all members in achieving the Center's goals. We were the first organisation of persons with disabilities in Serbia to start the ball rolling on the social model of disability, and coupled with the philosophy of independent living, we've been promoting them for twenty years in every sphere of the Center's activities: choice, independent decision making, control, responsibility and the right to make mistakes, for people with disabilities.

Our key achievements are that, through its twenty-year life, the Center has managed to leave a significant mark on the field of disability and shape attitudes towards and policies concerning persons with disabilities, on the disability movement in Serbia, and the quality of life of persons with disabilities.

In terms of shaping attitudes and policies, the Center has made a major contribution to embracing the social model of disability and changing attitudes towards persons with disabilities in Serbia, who are viewed less and less as passive recipients of other people's care and handouts, and are increasingly considered active, equal citizens whom society must provide with equal opportunities for full participation in all spheres of social and political life. Only thus can we exercise our human rights, develop our full potential and contribute to society. Of course, we advocate the same opportunities for organisations of parents of children and persons with disabilities who cannot fully advocate their rights. The Center participated in the adoption and amendment of numerous pieces of legislation and documents for the benefit of persons with disabilities, and through my work as an MP of the National Parliament of Serbia, I, as a member of the Center, contributed to raising awareness of the rights of persons with disabilities among both those in the corridors of power and the wider public in Serbia.

The work done by the Center has also spurred the development of the disability movement and gained acceptance for the social model in the activities of many organisations of persons with disabilities, and thanks to the work of the Center, the disability movement now has nine new local branches of the Center[96], which are among the most enterprising organisations of persons with disabilities in their communities.

When the Center was in its infancy, I designed a special education programme and created the Center's own pool of coaches, persons with disabilities. Alongside our colleagues, and under the auspices of the Center, we held over a thousand seminars and workshops throughout the Balkans and across fifty cities in Serbia, spreading knowledge and raising awareness about models of disability, the philosophy of independent living, international and national documents, public relations, advocacy skills, discrimination and in particular double discrimination against women with disabilities. Together with Mimica as a co-author, I designed a personal assistant training programme,

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[96] Local Centers for Independent Living are located in Sombor, Belgrade, Kragujevac, Smederevo, Leskovac, Jagodina, Čačak, Bor and Niš. (Ed.note)

which is accredited by the Republic Institute for Social Protection, and which to date has been delivered in fourteen cities in Serbia, with over three hundred recipients of official personal assistant qualification certificates from the Republic Institute for Social Protection.

Thanks to the Center's work, disability movement activists in Serbia no longer mention persons with disabilities purely in the context of healthcare and social protection, but also in the areas of equality and non-discrimination, employment, education, access to the physical environment and information and gender equality and political action. In addition to the Center's publishing activities, all of this has contributed to efforts to empower persons with disabilities and their organisations, and encourage them to play a greater role in advocating their rights.

Photo from the event to mark the 20th anniversary of the Center for Independent Living Serbia, 2016

You've also brought about change in the quality of life of persons with disabilities?

Rallied around a new idea and a new way of working, many persons with disabilities have improved the quality of their lives, acquired new knowledge and skills, regained their self-confidence and dignity. We are coming in from the cold and we refuse to be reliant on the good will of certain decision makers, we demand access to our human rights, because, as I said, if we perceive ourselves as defenceless, so will others.

The positive effects on the quality of life of beneficiaries are reflected in our experiences, the knowledge that we can organise our lives differently and for the better and empower and motivate us to further develop our capabilities and potentials. In that way, we become "models" and examples for other persons with disabilities to step away from being merely “bystanders to their lives” and to start really living their lives.

What I think is also important is that I tried to persuade my friends with disabilities to make themselves look more presentable. I “badgered” some of my friends to change how they dressed because they were forever dressed in tracksuits, runners and the like.

When we went with EDF on the study visit to the Parliament in Brussels, I told our friend Paja that there was no question of him going to the European Parliament dressed in a tracksuit and making “a holy show” of us there. They might have let him in out of pity and turned a blind eye to the runners, but a dress code is a dress code! He was under orders to get himself a suit. He replied: - “I can’t wear a suit. You haven’t a clue how impractical, awkward, etc., they are.” – I retorted: “Shoes can be bought two sizes bigger, trousers one size bigger, and I’ll sew on an elastic band so that you can take them on and off like a tracksuit, and you’ll have a jacket on over it so it won’t be visible.” Aside from Paja, I gave the same “lecture” to Dimitrije, Sveta, Vojče. So off they went to buy suits and one by one they called me to tell me they’d bought a suit. Dimitrije was the only one you couldn’t completely “reform” (he’s just not that kind of guy), he never owned a suit, but he did buy some trousers or jeans, I can’t remember, shoes and a velvet jacket. It was still a better look than a tracksuit. Nowadays they wear suits and ties to all formal occasions, meetings, conferences and look most elegant. I was reminded of that recently when watching a documentary about the struggle of the American disability movement “Lives Worth Living”[97], in which one activist tells his colleague: - “They can arrest you, it doesn’t matter, but just make sure you have a clean shirt and tie, and suit because you represent the Center for Independent Living at Berkeley.”[98]

From the reception at the White Palace in 2006

I remember a photo from a reception at the White Palace in Belgrade for a presentation of donated wheelchairs, which shows a group of wheelchair users

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[97] Eric Neudel’s documentary “Lives Worth Living” about the history of the civil rights movement for persons with disabilities in the United States, made in 2011. (Ed.note)

[98] Berkeley is a university city in California, where the first Center for Independent Living was founded in 1972 (Ed.note).

sitting in T-shirts, tracksuits and runners, and right in among them all are Paja, Sveta and two or three other colleagues all dressed up to the nines in their suits. I was thrilled that they were in those suits. Those are some of my favourite photos. You can see Sveta, suited and booted, glasses, tie...Mimica nicknamed him “adžija”.[99]

I must admit that I’m not easy to work with. I usually set goals for myself and then for my closest associates, goals that are either not possible or certainly not easy to achieve, so I expect the same from them as well. I’m a perfectionist in my work, which is not good, and I expect the same from others. This is, of course, a fool’s errand, because, as Mimica is fond of saying, you can’t get blood out of a stone. Although I know all this in principle, I find it difficult to stop myself from doing it, which at the end of the day has its price. Some people get tired of it, so they move on to other fields of work, and others get used to the fact that I have to double check everything, and then they take the foot off the pedal because they expect me to “put it right” when all is said and done. I often forget to praise people for doing a job well, but I somehow never fail to tell them what could have been better because that’s how I was treated when I started out on my career. The unfortunate thing is that I take that approach with my closest associates, who I care about the most, and whom I really love. Although I’m trying, it’s a bit late in the day for me to change my ways and they’re well used to me as I am, so I hope they don’t resent me too much and I know that they love me too.

How did you achieve your goals?

Apart from continuous political work and lobbying for systemic and legal solutions, the Center operates mostly through projects. Over these last twenty years, we have implemented over seventy projects, of which:

- fifteen projects specifically related to the promotion of PA services, although we tried to incorporate the independent living component in all the projects we worked on
- thirty-four projects related to education in the field of disability rights, protection against discrimination, raising awareness of disability issues, accessibility
- four projects were or are of a regional character in which the Center is the representative of organisations of persons with disabilities for Serbia
- five projects examined poverty in marginalised groups in Serbia, and the Center examined in detail poverty among persons with disabilities

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[99] “Adžija” is the honorary title given to a person that has carried out his/her mandatory religious duty i.e. the pilgrimage to Mecca. (Ed. note)

- twelve projects related to issues of women with disabilities, research, and capacity building for our organisation

To quote from our film[100] "The idea that is still flowing":

We believe in the power of making new choices, in taking it step-by-step The best is yet to come.

We used to sail in the moonlight, hoping for happy sail and our chance to shine. There were naysayers aplenty who didn't want us to succeed. But we have changed, because when the day breaks and the clouds part, our sail is splendid.

We believe that each being is unique in its own way and that this uniqueness is the best we have to share with the world. We believe in our uniqueness. We were and are unique. We share it with everyone, we welcome all who want to join us and respect those that don't - diversity and everyone's uniqueness are riches.

We trust and respect our mentors and "pay" the knowledge forward. We are forever appreciative of our mentors, we continue to learn and are not reluctant to go in search of new knowledge, while happy to pass it on to those who want to adopt it.

We have conducted and published twelve of our research works covering various areas of the lives of persons with disabilities and published over thirty other publications, enriching the hitherto extremely scant corpus of documented information about persons with disabilities.

We believe we are here to help each other. There is always someone in need of support.

We believe that nothing is so good as to be true and that the limit of our imagination is not the limit of the world. Thomas Edison said: "When you have exhausted all possibilities, remember this - you haven't."

We believe that things can get better, much better, we will not stop…

We believe in ourselves - that we can control our lives, from one day to the next.

We believe in our tenacity to hold our course.[101]

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[100] The film can be found with English subtitles at this link: https://www.youtube.com/watch?v=wyOx_EwzBsk

[101] Taken from the film "The idea that is still flowing" produced by the Center to mark its twentieth anniversary (author Mimica Živadinović) (Ed. note)

Your activism brought you to places far and wide.

Pictured at the International Leadership Forum for Women with Disabilities in Washington in 1997 with a colleague from India

Indeed! My travels are some of my most cherished experiences and memories. Those memories and the people you encounter and get to know are something that no one can take away from you, even when you lose all your worldly possessions. Recollections that stay with you for the rest of your life. Most of my travelling was done with Mimica, my close friends and some of my assistants.

I've already mentioned some of the trips I went on while working at the Muscular Dystrophy Association of Yugoslavia, and later at OXFAM, and the Center. I've travelled to every European country including Georgia, save for Portugal, Bulgaria, and Turkey. I've been to the Middle East, Lebanon and Bangladesh on the border with India. Also, I travelled to Canada and the United States, and to China.

One of those trips that I remember is travelling to Washington in June 1997, to the International Leadership Forum for Women with Disabilities. There were about six hundred women from all over the world at the Forum. It was intriguing and remarkable to see women with disabilities from many countries setting the pace, including prominent women leaders of the disability movement especially from the United States, whose attendance lent additional backing and impetus to other Forum attendees.

The key areas discussed were leadership, education, health and family, communication and technology, and employment. The conference was opened by Madeleine Albright, US Secretary of State, and it was an incredible feeling to be at an event attended by six hundred women with all forms of disability of all races, and yet to feel a great sense of belonging and togetherness and a desire to break down the barriers to women with disabilities being put on a completely equal footing.

It was there that I first met Judith (Judy) Heumann in person, one of the leading lights of the U.S. disability movement, who served in the Clinton Administration as Assistant Secretary of the Office of Special Education and Rehabilitation Services at the US Department of Education, then served as the World Bank Group's first Advisor on Disability and Development, and then as Special Advisor on International Disability Rights for the U.S. State

Department during President Barack Obama's tenure. I later met her at various events throughout Europe, and she travelled to Serbia twice, the last time in October 2015, when she toured the region and delivered talks about the rights of persons with disabilities.

Gordana with Judy Heumann, 2004

The other thing I will always remember is that the first day after my arrival, my electric powered wheelchair broke down. They pointed me in the direction of a repair service centre where they might be able to repair wheelchairs manufactured in Europe. To get there we had to travel by train. In the end, the wheelchair couldn't be repaired and I rented another during the conference. However, at the repair service centre I met a quadriplegic man who it stands to reason used a wheelchair and couldn't even use his fists. He asked my friend Milena, who had accompanied me, to light a cigarette for him. As we were about to leave, he offered to drop us back by car, which of course we gladly took him up on, and when we got to the car I noticed that there was no driver. I asked who was going to drive us, to which he replied: - "Well, I am." I got into this enormous van with trepidation, which he got into with the help of a mobile wheelchair platform. He then settled into the cab and drove the car not with the help of the steering wheel, rather with the help of a joystick. We were addled. But all I was concerned with was getting back to the conference venue safe and sound. That was my light-bulb moment as regards the possibilities that technology holds.

Gordana at the Disabled Persons' International World Summit, Winnipeg, Canada, 2004

The second big event that I also remember well and which I attended as a delegate of persons with disabilities from Serbia, was the World Summit organised by Disabled Peoples' International and held in September 2004, in Winnipeg, Canada, addressing the theme "Diversity Within". It was attended by Disabled Peoples' International representatives from various regions, organisations of persons with disabilities, other non-governmental, international organisations, and service providers from one hundred and thirty-five countries with a total of about eight hundred delegates. The theme of the summit was, in fact, the diversity of persons with disabilities and their cultures, with a special focus on women, youth, indigenous peoples of Canada and America (Indian Nations) and indigenous Arabs. Over thirty different workshops were held over three days to address current issues in disability movements in various countries, and to create a road map for the future covering themes such as the human rights of persons with disabilities, independent living, and bioethics. The summit was also called the "Global Disability Village", where participants could exchange information and research on many aspects of disability issues. It that sense we were spoilt for choice. I participated in several discussions, especially those that were dedicated to women with disabilities and independent living. I had never participated in an event of that magnitude before and it was a unique experience.

Travelling to the summit was also quite the experience. I flew from Belgrade to London, then from London to Montreal, and then from there to Winnipeg. The return trip took me from Winnipeg to Toronto, then to Paris, and then from Paris to Belgrade. A "round trip around the world" such as this presents the perfect scenario for luggage or parts of the wheelchair to go missing and that is exactly what happened to me on the outbound journey. I spent three days of the summit wearing the same leggings and a winter hoodie because the venue was on the outskirts of the city and there was no possibility of going clothes shopping nearby. My luggage arrived the evening before I left, so at least I turned up to the closing dinner in the appropriate attire. I'll always remember that trip, that's for sure.

And finally, another great trip that left a profound impression on me was my trip to the Paralympic Games in 2008 in Beijing. I travelled as a member of the state delegation together with members of the Paralympic Committee, in place of the Minister of Youth and Sports Snežana Samardžić Marković who had to withdraw from the trip at the last minute. It was truly an unforgettable event, from the spectacle at the Opening Ceremony of the Paralympic Games, to following the individual performances by our Paralympians. I remember the excitement in the stands as we watched the finals of women's table tennis, where Serbian athlete Borislava Perić Ranković a.ka. "Beba" from Bečej and Chinese athlete Zhou Ying battled it out for gold. Beba had come up against her in finals for years, but she always took home the silver medal, having in mind the number of competitors in China and the fact that table tennis, according to some historians, originated in China.

At the last Paralympic Games in Rio de Janeiro in 2016, Beba finally managed to get the better of her and win an Olympic gold medal. Our other Paralympians had considerable success also. In addition to watching our Paralympians compete, I also went to watch the swimming where I was completely fascinated to see competitors, who had only parts of their arms or legs, put in dazzling performances in the pool, and even breaking some world records of Olympic competitors.

Gordana with Beba (second from the left) and part of the Serbian Paralympic team in Beijing in 2008.

Of course, we also had a little time to visit the Forbidden City and the Imperial City, but it’s impossible to describe what these buildings look like with all the features of Chinese culture and painting. Even these exceptional historical and cultural sites have been adapted to make them wheelchair friendly, with clearly marked, obstacle-free routes. Even the famous Great Wall of China was accessible up to a certain level, some sections of which were serviced by ramps, and others by panoramic elevators that allowed you to climb a part of the Great Wall of China using a wheelchair. It was awe-inspiring to see the effort the Chinese authorities have made to make all these sites accessible to persons with disabilities. It was a once in a lifetime trip if you are lucky and it remains a lasting memory of an unusual distant world.

What characterises your path in life?

I think I lead a fulfilling and meaningful life. I reckon I’ve lived the equivalent of at least three ordinary lives given everything I’ve done and been through. This much is certain: my life has not been easy considering that I’ve spent it alone, without the support of a family which others can usually bank on to regain their strength and motivation to push on. If I add to that the fact that I’ve been coping with muscular dystrophy for sixty years, which is a very serious disease that day by day “robs” you of some part of your muscles and renders you more and more physically dependent on other people’s assistance, then it’s plain to see that life hasn’t been plain sailing all these years. A recollection of an event from twenty-five years ago always helps me put this slightly gloomy picture to the back of my mind. Namely, I have a special type of dystrophy, the clinical picture of which can reveal several neuromuscular conditions, some of which can be halted and even restored. The most reliable way to determine this is a diagnostic method called a “biopsy”, in which a part of the muscle is extracted and sent for histopathological analysis to accurately identify changes in the muscle. For years on end I refused to do it, but then Professor Slobodan Apostolski, PhD.,[102] convinced me that it was imperative. I relented and a piece of my leg muscle was sent to the Histopathological Institute for analysis. The report was made by renowned histopathologist Prof. Dožić and after a few days he called Prof. Apostolski to enquire: - “As a matter of interest, when did this patient die?” So even though my muscles don’t seem very vital, they stubbornly refuse to disappear completely and I still somehow function with them!

Personally, as far as work is concerned, I am satisfied with myself because I managed to preserve the spirit that once existed in the Muscular Dystrophy Association of, as Mimica would say, “former Yugoslavia”, where people felt like members of the same family no matter how much our opinions differed, we always remained extremely loyal to the organisation. Organisations of that kind are a thing of the past. That’s why I’m very proud that we managed to convey that spirit and at least partially preserve it in the Center for Independent Living Serbia. I think our event to mark the Center’s twentieth anniversary captured that spirit. The event was attended by people from every grassroot organisation, from across the region, as well as people who have been long-time or one-time associates of ours and who are not part of the disability movement, and yet that spirit of belonging to the Center, friendship and love of one another has remained with them.

As in every life, so in mine, there have been ups, downs and failures. I haven’t spoken much about them here. Although I think it’s important that even after the setbacks and failures, I managed to pick myself up and move on.

Over the last three years I’ve suffered great personal losses as well as several bereavements. I haven’t mentioned my extended family in this conversation because only a couple of them very rarely supported me in anything, while most of them forgot I existed unless they needed something. That saddens me sometimes, but unfortunately, there is no glossing over it.

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[102] Prof. Slobodan Apostolski, PhD., neurologist, professor at the University of Belgrade

Our colleague Lepojka passed away, a steadfast collaborator in the fight against double discrimination of women with disabilities, as has our colleague and wonderful friend Sanja Zahirović, the wife of our great friend Suvad from IC Lotos from Tuzla, who, although a non-disabled person, like Mimica, was a fervent activist for the rights of persons with disabilities. And in Dublin, Ireland, the dear faces of my friend Judy, Florence (Flo) and Martin, without whom Dublin is no longer the same city, “my second home”, no longer await me. Each new bereavement adds a fresh, invisible layer of forlornness and sorrow to my life.

Despite that, I try to work, out of habit I suppose, because my entire life I’ve always kept busy and I marvel at how I find the strength to cross another new border, secure new free spaces for activities and rights of people with disabilities and it is those moments that spark my tenacity and enthusiasm, such as opening a new venue for political action of persons with disabilities and raising awareness of the need for such action as part of a project run by our Center.

Gordana with Luka in Dublin, 2011

The most beautiful part of my life was when Mimica gave birth to her son Luka in 1995 and chose me to be Luka’s Godmother. My great unfulfilled lifelong wish to have a “child of my own” had come true. My “godson”, little Luka, grew up alongside me and I’ve found it an amazing and wonderful experience to watch him grow, teach him some new things, read books to him, take him on excursions, take care of, be proud of and rejoice in his successes - a feeling which probably every parent in the world has. All the feelings - happiness, joy, pride, worries - became somehow purer, clearer, as if someone had suddenly switched on a light in my life. I’ve watched him flourish into a delightful, fine young man with a smile to die for. I’m grateful because life and Mimica gave me a chance to fulfil my greatest lifelong wish: to “have” a small family of my own.

How would you like us to round off our conversation?[103]

I can't decide. There would be no soul to it if we were to wrap it up discussing activism and political messages. It would give the impression that I don't exist in the flesh, that I'm just a product of my work. Therefore, in this story about my life I've shared some private and very personal events, trying to do it with the right measure while maintaining my privacy.

I get scared every time I think of the number: fifty years of work in the disability movement. That's a whole human lifetime, sometimes more. And when I look in the rear-view mirror of life, I've no idea where all the years have gone, and what I was actually doing. But I can tell you one thing for sure: my greatest treasure over these fifty years is people. The people I encountered, met, learned from, shared my ideas, my thoughts with...those I worked alongside, and I sought to share my knowledge and experiences with everyone who had an interest in hearing them. I think that I managed to touch their lives to some extent through that work and tried to motivate them to take a different view of life, to regain their dignity, the quality of their life and to really be themselves, as people worthy of every ounce of respect.[104]

I once read somewhere that life is like travelling by train. People get on and get off. When we are born and board the train, we meet people we think will accompany us for our entire journey. Unfortunately, someday they will alight the train and leave us without their love, care, tenderness, without their friendship and company. Their seats will remain empty and awaken the sorrow within us. However, others will board the train, who will also come to mean a lot to us.

The biggest mystery of the journey is that we don't know when we will alight the train forever. However, I harbour the hope that there is a central station and that there I'll meet the dear faces of those who alighted before me, as well as see how those closest to me arrive, with the luggage they weren't carrying when they boarded the train. It would gratify me to think that I helped them add to their luggage and that I filled it with the requisite effects. I'll be glad to meet them again. I too would like to leave an empty seat behind me when I get off the train, one that evokes fond and pleasant memories for other passengers continuing their journey.

In closing, I would certainly like to thank all the people who have passed through my life, supported me, were a part of my life for at least part of it, and I believe that I was a part of their lives. There are many people I would like to

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[103] The answer to the last question was supplemented by the interviewee when signing off on the transcript. (Ed.note)

[104] Part of the closing address delivered at the twentieth anniversary of the Center for Independent Living, held at the Holiday Inn Hotel, on 5 May 2016, on the European Day of Independent Living. (Ed.note)

mention, for example, my friends and associates at the Center for Independent Living and beyond (Moma, Suvad, Sveta, Dimitrije, Sanja Nikolin, Vesna Cipruš[105], Hasan), but this venue and this book do not lend themselves to it.

Nevertheless, I want to mention my friends who have been with me on the train of life for decades, such as Lola, Ljilja, Vesna, Milena[106], Desa too, who has been living with me for sixteen years, who helps me and completes our small household, Anči[107] who has been with me as a personal assistant for more than twenty years although we're not friends in private. But above all, I harbour a special love for and gratitude to my Mimica, "my kumašin[108]", co-worker, friend, member of my small family, for all the care, attention, support, help and love she has selflessly given me for thirty years. With the support and love of them all, I managed to do some good in life.

Of course, Mima, you in particular have my sincere gratitude for the fact that you decided to write your doctoral thesis based on my life story. Without your initiative, perseverance and effort, this book would never have been written. I myself would never have had enough desire to do it despite numerous people having suggested to me that I ought to document all my experiences.

Milica Mima Ružičić Novković, M.A., February 15 and 16, 2016, amended on May 5 and 19, 2016 and during transcript sign-off during March and April 2017

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[105] Sanja Nikolin and Vesna Cipruš, Experts and advisors in the field of social protection and public policy, long-standing associates of the Center for Independent Living (Ed.note)

[106] Jovanka Andrejević – Lola, Ljiljana Savić, Veselinka Kastratović – Ristić, Milena Šarenac (Ed.note)

[107] Anđelka Janićijević (Ed.note)

[108] „Kumašin" is a nickname for mother of my godchild (Ed. note)

Appendix 1

BIOGRAPHICAL TIMELINE

GORDANA (1944), Belgrade

Recorded by: Milica Mima Ružičić Novković
Transcription: Biljana Radusin
Editorial staff: Milica Mima Ružičić Novković and Svenka Savić
Recorded on: February 15 and 16, and May 19, 2016 in Gordana's apartment in Belgrade and May 5, 2016 in the Holiday Inn Hotel in Belgrade.

1944 Born in Vračar, one of the boroughs of Belgrade (in a two-room rented apartment) not far from the Temple of St. Sava, to an Orthodox father, shoemaker, originally from Bešenovo in the Banat, a mother from a mixed marriage (Ukrainian grandfather, Austrian grandmother) originally from Stari Mikanovci in Slavonia, seamstress, Resistance Movement activist during World War II, and Communist Party activist post-liberation.
1946 Birth of her brother.
1950 Starts school at the "St. Sava" primary school in Vračar.
1955-56 Diagnosed with muscular dystrophy at the Neurological Clinic in Belgrade.
1958 Enrolled at the XIV Belgrade Comprehensive School.
1961 Passing of her father.
1962 Her family moves to an apartment in Maksima Gorkog Street in Vračar.
1962 Enrols in October to read mathematics at the Faculty of Natural Sciences and Mathematics, University of Belgrade.
1963 Passing of her mother in June. Her brother enlists in the military (the Navy) in September.
1964 Visits the Department of Neurology in Zenica, where Dr. Geza Čeh treats people with muscular dystrophy with Italian injections of Miotip and Stenoplex. Her brother moves to Germany following his discharge from the military.
1966 In Banja Fojnica, co-founds the Muscular Dystrophy Association of Yugoslavia, in charge of membership, and then (with two other colleagues) in charge of negotiating with institutions for legislative change.
1967 Starts working as a maths teacher in her apartment (she gives grinds to secondary school and university students).
1968 Secretariat of the Muscular Dystrophy Association of Yugoslavia opens in Belgrade, the Council of Experts of the Muscular Dystrophy

Association of Yugoslavia and the Muscular Dystrophy Association of Serbia are established. Gordana was also one of the founders of the association both at the federal and state level.

1969 A new Hospital for Rheumatic and Myopathic Diseases opens in Fojnica near Sarajevo. Gordana fundraises.

1970 She helps with establishing the European Alliance of Muscular Dystrophy Associations (EAMDA) in London.

1970-1974 Advocates for legislative changes in the fields of healthcare and social protection, lending support to scientific research in the field of neuro-muscular diseases and other areas key to improving the position of persons with neuromuscular diseases.

1976 Elected the first woman President of the Muscular Dystrophy Association of Yugoslavia. Also tasked with organising the EAMDA general assembly, held in Belgrade at the Hotel Yugoslavia, where, for the first time, she used a wheelchair and wheelchair assistance.

Awarded the Order of Labour with Silver Wreath by Decree of the President of the Socialist Federal Republic of Yugoslavia (SFRY) for achievements at the Muscular Dystrophy Association of Yugoslavia. She is the only woman among the five decorated people with muscular dystrophy.

1982 Editor of the *Miopatija i mi* newspaper published by the Muscular Dystrophy Association of Yugoslavia (until 1989), which was first published in 1968.

1986 Awarded the Order for Services to the Nation with Silver Rays by Decree of the Presidency of the SFRY for Special Merits and Achievements of Importance for the Socialist Development of the Country as the only woman, a person with muscular dystrophy, among the seven recipients.

1987 Makes the acquaintance of Mimica Živadinović who started working as a technical secretary at the Muscular Dystrophy Association of Yugoslavia, with whom she later lived for eight years, who was her first personal assistant of sorts and with whom she has worked for over thirty years and enjoys a deep-rooted friendship and family relationship.

1991 She was elected President of EAMDA (as the first woman to hold that office), while EAMDA secretary general was Judy Windle from Ireland. It is at that general annual assembly in Ljubljana that she makes the acquaintance of representatives from Ireland.

The Muscular Dystrophy Association of Yugoslavia, where Gordana and her colleagues have volunteered for 25 years, officially ceases to exist. The associations at republic and provincial levels continue their work in the newly formed states after the disintegration of the SFRY.

Liaises with the Danish and German muscular dystrophy associations with a view to evacuating a group of people with muscular dystrophy from Bosnia and Herzegovina.

1992 Travels to Sweden with Mimica Živadinović to attend the EAMDA general assembly, where she tables a motion to fundraise for the evacuation from Sarajevo to Germany of a group of members of the Muscular Dystrophy Association of Bosnia and Herzegovina, which President of the German Muscular Dystrophy Association Gergor Schwartz played a major role in bringing off.

After the Executive Committee meeting in London, of which she remains a member, and at the invitation of EAMDA secretary general she travels to Dublin with Mimica for two weeks to escape the situation in Serbia at the time.

Organises a seminar for the Muscular Dystrophy Association of Ireland, after which Mimica returns to Belgrade and she remains in Dublin for another 5 months at the invitation of the Dublin Center for Independent Living which has just been established, to help with the running of the centre and educational programmes. It is at this point in time that she moves in with Florence Dougal who has just started living independently.

1993 Lecturer at the first disability studies course at Maynooth University in Dublin. Participates in the work of the EAMDA general assembly in Aarhus, Denmark.

1994 Manages the Operation Get Out project in Dublin. Participates in the work of the EAMDA general assembly in Glasgow, Scotland.

1995 In April, manages and organises the international symposium “Disability - An Investment, Not a Burden on Society” in Dublin.

Returns from Ireland to Belgrade, where she works for the British humanitarian organisation OXFAM, first as deputy head of office, and until the end of OXFAM’s mission in this region as a regional advisor for disability issues.

In November, calls a meeting to discuss the formation of the Center for Independent Living for the Disabled of Serbia (today the Center for Independent Living Serbia), which represents the formal beginning of the independent living movement in Serbia.

Designs the first training programmes on “Full Participation and Equality”, participating as a trainer on training courses for persons with disabilities and their organisations (until 2010).

1996 In February, the Center for Independent Living Serbia is registered. Somewhat later that year, the Center for Independent Living Serbia joined the European Network on Independent Living (ENIL) as a full member, with Gordana a member of the ENIL Executive Board until 2011.

1997 Represents Serbia at the Women with Disabilities International Leadership Forum in Washington, USA, which brought together over 600 women with disabilities from around the globe.

1999 The NATO bombing campaign finds her in a third floor apartment in Maksima Gorkog Street, Belgrade, and on May 6, bombs rain down on the house across the street, compelling her to move out temporarily, with no access, for the next three weeks.

2000 Organises the first regional conference of women with disabilities in Ohrid, Macedonia, for women from the region (Croatia, Bosnia and Herzegovina, Serbia, Montenegro, and Albania). That same year she moves into the apartment where she now lives and which is more accessible.

2001 The Center for Independent Living Serbia, with support from OXFAM, organises the first training course for trainers in the field of disability among disability movement activists.

2002 At Gordana's suggestion that the personal assistant service be piloted in Belgrade through the Emergency Situations Program, OXFAM allocates the first round of funding for this service for people with disabilities for a period of three months for 12 beneficiaries. At the end of the pilot project, together with Borivoje Ljubinković, she co-authors a research paper: "Personal Assistant Service as an Alternative Form of Support for the Disabled".

2003 Arranges for the Government of the Republic of Ireland (at the suggestion of the Honorary Consul of the Republic of Ireland through the mediation of a then UNICEF official, whom she knew from joint emergency response services meetings) to allocate funds via Irish Aid to Catholic Relief Services for a three-year pilot personal assistant service for seventy beneficiaries in five cities across Serbia, including drafting the required cost-benefit analyses and beneficiary quality of life impact reports. This project named SPAS runs for four and a half years in total, having a profound impact on the development of the independent living movement in Serbia.

2004 Travels to Dublin as part of a delegation from the government of the Republic of Serbia and the Center for Independent Living to present the first results of the project and to showcase the PA service to the representative from the Ministry of Social Policy.

In December, celebrates her sixtieth birthday at the Hotel Yugoslavia.

2005-2006 The Center for Independent Living Serbia has a decisive impact on and participates in the adoption of the Prevention of Discrimination against Persons with Disabilities Act, the new Construction and Spatial Planning Act, which recognises accessibility standards, and in the adoption of the first ever National Strategy to Enhance the Position of Persons with

Disabilities. She plays a negotiating and mediating role in the legislation adoption process.

2006 The Center for Independent Living Serbia marks its ten-year anniversary by organising a ceremonial academy at the Sava Center in Belgrade. As part of this celebration, a seminar on independent living and its philosophy is held in Bečej for the members of the Center, where an address is given by Dr. Adolf Ratzka, PhD., from Sweden, a well-known activist and founder of independent living movement in Europe.

2007 Elected as an MP, as the first person with a disability to the National Parliament of Serbia.

Nominated that same year by the US Embassy as the first woman from Serbia for the international "Woman of Courage" award, presented by the United States Government[109].

As part of the European Disability Forum's CARD programme, run by the Center for Independent Living, Gordana works to establish and formally register the National Organization of Persons with Disabilities of Serbia - NOOIS.

After NOOIS is established she takes up a position on its management board.

2007 Elected as an MP to the National Parliament of Serbia as a non-party member. Over two terms (2007-2012), she works on drafting several laws, including the Occupational Rehabilitation and Employment of Persons with Disabilities Act. During her term of office as an MP, she submits over 150 legislative amendments, of which over 90% were adopted and incorporated into legislation that has advanced the needs and rights of persons with disabilities.

2008 Research team member for a Social Protection Service for Persons with Disabilities project entitled "Exploring the Gap between Policy and Practice".

2009 Participates in a project funded by the United Nations Development Program - UNDP, which looks at existing capacities of organisations of persons with disabilities and increasing their advocacy capacities.

Manages the project: "Capacity Building for PWD Organisations for Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities", and a shadow report drafting workshop funded by the EU Office through the European Instrument for Democracy and Human Rights (EIDHR) programme.

2010 Manages the project: "Civil Society for Responsible Government and Poverty Reduction in Serbia", supported by the Norwegian Embassy, together with four other partner organisations representing various discriminated groups, which serves to give an insight into budget planning, allocation and spending controls at national and local level.

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[109] United States Department of State (Ed.note)

2011 Serbia’s Social Protection Act is adopted. Gordana is a member of the working group and involved in negotiations with the relevant ministry. At the same time, together with Mimica Živadinović she designs the first ever personal assistant training programme, which is accredited by the Republic Institute for Social Protection; she serves concurrently as an MP in Parliament and is entrusted with liaising between NOOIS and Parliament.

Becomes a member of the Local Advisory Group (LAG) that operates as part of the Technical Assistance to Civil Society Organisations (TACSO) project, a European Commission mechanism that supports civil society organisations in non-EU countries.

2012 Manages the project: “Together for the Political and Economic Empowerment of Persons with Disabilities”, which sees the formation of Serbia’s first ever Parliamentary Working Group for Persons with Disabilities. The project is funded by the EU Office in Serbia through the EIDHR programme; she serves concurrently as an MP in Parliament. In June, appointed a member of the Council for the Rights of Persons with Disabilities of the Ombudsman’s Office of Serbia.

2013 In January, admitted to the Hall of Fame of the European Network on Independent Living - ENIL, which honours the leading activists of the independent living movement in Europe. Helps to implement the regional project entitled: “Establishing the Balkans Independent Disability Framework”, together with partner organisations from Bosnia and Herzegovina, and Montenegro. As part of the project she heads up a compliance analysis of Serbia’s legislative and institutional framework with the UN Convention on the Rights of Persons with Disabilities and recommendations for harmonisation.

2014 Continues to work. Involved in preparing an application by the Center for Independent Living to the Ministry of Labour, Veterans’, and Social Affairs for licensing of a personal assistant service.

In July, the Center for Independent Living is granted the first ever full licence to provide this service in Serbia.

2015 Director of the project: “Increasing Political Participation by Persons with Disabilities in Serbia”, in partnership with NOOIS, funded by the United States Agency for International Development - USAID. As part of the project the Parliamentary Working Group for the Empowerment of Persons with Disabilities in Politics is re-formed and change is set in motion to make the election process more accessible for persons with disabilities in cooperation with the Republic Election Commission.

2016 In Geneva, together with the executive director of NOOIS she presents the shadow report drafted by the Center for Independent Living Serbia and the NOOIS concerning implementation of the Convention on the Rights of Persons with Disabilities in Serbia before the UN Committee on the Rights of Persons with Disabilities.

The European Day of Independent Living, May 5, marks the twentieth anniversary of the Center for Independent Living Serbia.

Gordana celebrates half a century of involvement in the disability movement (which came to pass on November 6, 2016).

“This book, which comes at the dawn of the 21st century, sees Milica Mima Ružičić Novković from the Centre “Living Upright” continue her collaboration with other organisations operating in the same sphere (the “Women's Studies and Research” Association, Novi Sad publishing house Futura Publication) in the same spirit as Gordana Rajkov collaborated with others in pursuit of an overriding goal - improved independent living for disabled persons at the end of the last century. This has ensured generational female continuity that lends impetus to the Movement. Both have emerged as two truly exceptional women.”

Professor Emeritus Svenka Savić

Centre „Living Upright”
Center for independent living Serbia
Association „Women studies and research”
Futura publication

Milica Mima Ružičić Novković (1978, Novi Sad), graduated from the Faculty of Philosophy in Novi Sad, Department of Serbian Language and Linguistics and defended her master's thesis at the same department. She is a doctoral student in gender studies. She coordinates the Programme for Equality of Disabled Persons in Public Speech run by the Centre „Living Upright”, which she has headed since 2004. Her research centres on the language of disability, and equality of marginalised communities in public speech.