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Darja Zaviršek

HANDICAPPED MOTHERS – HANDICAPPED CHILDREN

THE ANTHROPOLOGICAL PERSPECTIVE ON SOCIAL DISABILITY OF MOTHERS AND CHILDREN IN SOCIAL WELFARE AND SOCIAL WORK

Dr. Darja Zaviršek is associate professor at University of Ljubljana Faculty of Social Work.

The paper is based on the concept of civic handicap experienced by minority children and their mothers. It is understood in the widest sense, not as limited to physical and mental impairments but as describing socially constructed handicap causing unequal opportunities. The civic handicap may be transgenerational, passing from parents to children. The handicap of Roma children, for example, is a consequence of their parent's as well as their community's handicap. Conversely, children's handicap may transfer to their parents. The parents of a handicapped child will on this account themselves suffer many handicaps. The first part of the paper presents a critical analysis of the mother's experiences and her personal narratives about their perception of the child and what meaning they ascribe to the handicap. The second part presents a critical analysis of two concepts, the 'child-centred perspective' and the 'modernisation of childhood', showing that neither takes into account minority children. The double criteria are often characteristic for the treatment of the Roma and the handicapped children. The paper also discusses the skills and methods of work that the social worker should master while working with the handicapped children's mothers and with the minority children.

Keywords: civic handicap, »child-centred perspective, modernisation of childhood, minority children, institutionalisation, double criteria.

Lena Dominelli

GENDERING DISABILITY

Prof. Lena Dominelli is the Director of the Centre for International Social and Community Development at the University of Southampton. She was also President of the International Association of Schools of Social Work from 1996 to 2004.

The paper highlights the exclusion of disabled women from dominant discourses about disability to indicate the differentiated experiences of disability both amongst women and between men and women. It argues that disablism is responsible for this particular form of exclusion and focuses on its roots in both patriarchal and able-bodied views of the world. It also reveals the invisibility of disabled women within analyses put forward by the Disability Movement and through the collusion of practitioners engaged in professional practice with disabled men and women. It makes suggestions about how working with disabled people can be undertaken in a more egalitarian relationship that recognises their subjectivity and puts them in charge of events.

Keywords: disablism, gender relations, reproductive rights, mothering.

Elena Iarskaia-Smirnova

'ONCE UPON A TIME THERE WAS A GIRL WHO LIKED TO DANCE...'

LIFE EXPERIENCES OF RUSSIAN WOMEN WITH MOTOR DISABILITIES

Prof. Elena Iarskaia-Smirnova is Head of the Department of Social Anthropology and Social Work, Saratov State Technical University, Russia

The private sphere plays an important role in the lives of disabled people. It includes personal experience of disability on a micro level, in the family, in romantic relationships and in the routines of

everyday life. The article describes the role that the family plays in constructing the identity of a person with disability and how family members act as co-authors of individual biographies. The family builds hierarchies of age and gender, which reproduce social inequality within itself as well as in society. The article is based on the analyses of family stories of women who use wheelchair, and it gives evidence that family in many cases is unlikely to solve problems formed by the unfair organization of society. Family as a context for 'moral careers' and social mobility of the disabled women is considered, in order to learn to what degree the family structure reinforces or weakens the hierarchies of physical differences caused by disability, age and gender. The family and a number of other social institutions contribute to the reproduction of status hierarchy. This study glimpses into the real life of the families that, dealing with disability, accepted it and experienced a range of changes. The voices of women who live with disability help us understand that the family of the disabled may enter certain risk zones constructed by social conviction and lack of the social support on the side of professionals and community.

Keywords: family life, Russia, interview.

Dietke Sanders

BURDEN OR SUPPORT?

SOCIAL WORK IN THE LIFE OF MOTHERS WITH INTELLECTUAL DISABILITIES

Dietke Sanders is a lecturer at the department of social work and social pedagogy and a doctoral student at University of Applied Sciences Alice Salomon.

Women with intellectual disabilities are often seen as eternal children who need support throughout their lifetime and are therefore incapable of caring for anybody else. Thus mothers with intellectual disabilities are a living contradiction – a grown up child as well as a dependent carer. They turn traditional hierarchies upside down: usually it is the non-handicapped people who are responsible for persons with disabilities and make decisions for them, not the other way round. Mothers with intellectual disabilities and their children live in a situation between risk, resilience and competence. Well-being of the children is the main argument against their right to have and raise a child. There is a tendency to see risks in such families not only as a result of the mothers' disability. Experiences with residential projects and in-house care in Germany show that women with intellectual disabilities already have parental skills or are able to learn to care for a child. Social work can support them, improve their parental skills and empower them to be 'good enough' mothers. On the other hand, social work can be a risk factor, concentrating on the mothers' deficits and burdening them with the pressure to be 'perfect' might finally cause them fail.

Keywords: decision-making, risk, independent living.

Barbara Ivačić

THE EXPERIENCES OF MOTHERS' OF THE DEVELOPMENTALLY CHALLENGED CHILDREN

Barbara Ivačić is an economist, an M. A. student of sociology of everyday life at University of Ljubljana Faculty of Social Sciences, a member of the section for the Down syndrome, and a mother of a child with the Down syndrome.

Systemic help to families with a developmentally challenged child mainly focuses on the problems of the child. Our qualitative research has provided some insight into the factors that determine the system mother-developmentally challenged child-family-environment. Structured interviews have been carried out with twelve mothers of developmentally challenged children. The data have confirmed that it is mothers who take over the greatest part of care. In general, they steer between, on the one hand, feelings of guilt and helplessness and fears, which are often reinforced by negative prognoses and information given by professionals, and on the other hand, their love for the child and the fight for the better future. In their efforts that their child should maximally develop his or her potentials they again meet what is called 'over-optimism and unreal expectations'. A great majority of

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interviewed mothers find that the 'misfortune' has changed their lives and has given them unexpected opportunities for personal growth.

Keywords: handicap, supportive environment, experience, interview.

Irena Ceglar

RELATION BETWEEN THE ADULT WITH INTELLECTUAL DISABILITY AND HIS OR HER MOTHER

Irena Ceglar is employed in the sheltered employment centre Tončka Hočevar in Ljubljana and a student of the specialist studies of social work with people with special needs at University of Ljubljana Faculty of Social Work.

The relation between adults with intellectual disability and their parents is socially conditioned. People with intellectual disability are still mainly treated from the medical standpoint based on needs. The parents of such children expect their child to remain dependent. Institutional care and once dominant approaches of professionals to the work with relatives reinforce the parents' impression that they will have to care as well as control their child throughout his or her life. A smaller research was conducted in order to illuminate the relation between adults with intellectual disability and their mothers. It was found that mothers are extremely important also in the adulthood of their children and that the bond with the mother is often the strongest emotional link. This may be explained with the extent of the social network in such cases, which tends to be limited to the primary family.

Keywords: caring work, dependence, bond.

Julijana Kralj

LACK OF EQUAL OPPORTUNITIES AND SUPPORTIVE NETWORKS FOR WOMEN WITH MOTORIC DISABILITY

Julijana Kralj is the President of the Slovenian association of people with motoric disability and a researcher of the specific situation of women with motoric disability and with medical diagnoses such as paraplegia, tetraplegia, hemiplegia, etc.

The paper presents the lives of women with motoric disability and with the medical consequences of the impairment of the spine or of illness, which influence the way of life of the user and the whole family. In most cases the women get accustomed to the changed way of life. Some, however, find it difficult to adjust. They feel it as a heavy physical, psychological and social burden. If in addition they are dependent in terms of finances, housing or in pure physical terms, they find it difficult to cope, they are more exposed to oppression and abuse, and they have less opportunities for self-help in a crisis situation. For a way out they need more help than women who have a positive attitude to life, strong personality, independent housing, and who are socially and economically well settled. Most participants in the research often experienced multiple abuses and cannot solve their problems without assistance. Despite the development of work in the field of violence prevention there is still much to be done for the disabled women who experience abuse and social exclusion. Further research is needed in order to adequately plan social services for the victims.

Keywords: violence, user's perspective, safe houses, visibility.

Mojca Urek

HIDDEN STORIES

WOMEN, HANDICAP, AND VIOLENCE IN THE FAMILY

Dr. Mojca Urek is an assistant lecturer at University of Ljubljana Faculty of Social Work.

The concept of handicap is not based on diagnosis; instead, handicap is 'measured' by the obstacles to independent living. Foreign researches show that women with disabilities remain in a dangerous situation twice as long as those without. The increased vulnerability is linked to many factors: they are less informed, more dependent upon carers and partners, and more isolated. Their statements are often taken as not credible, and the people around them often support their conviction that they

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are unable to get a better partner. One of the most aggravating factors is the inaccessibility of services. Beside physical obstacles, which prevent access, they may run into many other obstacles (sometimes they cannot call the police, it is more difficult for them to take refuge in a safe house). Safe houses do not provide continuing personal assistance that some women need; another obstacle is their lack of skills. A quick survey of the situation in Slovenia shows that despite the conviction that family violence suffered by disabled women is widespread, professionals are ill informed about their special living conditions, and that help is almost inaccessible to them.

Keywords: family violence, safe houses, counselling services.

Dušan Dvorščak

SEXUAL ABUSE AMONGST DEAF AND HARD-TO-HEAR ADOLESCENTS

Dušan Dvorščak, M. A., is a teacher of mathematics at the secondary school within the institution for the deaf and hard-to-hear in Ljubljana.

Various accounts show that there are few reports of sexual abuse in the central institution for the deaf and hard-to-hear in Ljubljana. There are many more cases of suspected abuse, mainly amongst the students in the institution themselves. Sexual abuse amongst them seems closely connected with the handicap of deafness, language and communication. The reasons for the higher probability of sexual abuse amongst them are sought in their being uninformed, in the ignorance of professional workers, in stereotypical ideas about the role of women in the society, about sexuality, about violence, and in particular in the discourse that dominates their schooling. Lower linguistic and communicational skills seem to be the main reason for the extremely low sensibility of the students for the occurrences of sexual abuse.

Keywords: sexual violence, communication, language.

Špela Urh

POSITION OF PERSONS LABELLED 'MENTALLY IMPAIRED', ESPECIALLY WOMEN

Špela Urh is an assistant lecturer and researcher at University of Ljubljana Faculty of Social Work and a graduate student at University of Ljubljana Faculty of Social Sciences.

Persons with intellectual disabilities may be children or adults, who are, on account of being categorised in this way, ascribed the lowest capabilities for schooling, employment, independent living, etc. Women with intellectual disability are disregarded even more. The Act of directing children with special needs (2000) and the Act of occupational rehabilitation and the employment of invalids (2004) are only partially based on the principles of integration and full inclusion of children and adults with intellectual disabilities into regular education and sheltered employment. The question remains whether that legislation promotes social inclusion of the people with intellectual disability at all.

Keywords: institutionalisation, integration, limited opportunities of women.

Zinka Kolarič, Liljana Rihter, Ružica Boškić, Tatjana Rakar
WOMEN USERS OF THE ORGANISATIONS FOR THE DISABLED

Dr. Zinka Kolarič is a professor at University of Ljubljana Faculty of Social Work. Dr. Liljana Rihter is an assistant lecturer at University of Ljubljana Faculty of Social Work. Ružica Boškić in Tatjana Rakar, M. A., are associate researchers at University of Ljubljana Faculty of Social Sciences.

The first part of the paper presents the crucial findings of the quantitative research that was carried out in invalid, charity and self-help organisations. The questions were: what existential situations, degree of disability and informal social networks characterise the users of their programmes, which of their needs are satisfied by these programmes, and in what extent do they provide a higher quality of life of the users. The second part is a discussion of statistically significant differences between female and male users of the services provided by invalid organisations, which show that the female users have less consumer goods at their disposal and more frequently limit their expenses for vaca-

tion and entertainment than their male counterparts. Female users more often live alone, without children or parents, and are less often married. They less frequently participate in the organs of associations and are more satisfied with the impact of services in the medical field and in the field of their personal safety,

Keywords: charity, self-help, quality of life.

Mateja Nagode, Polona Dremelj

GENDER DIFFERENCES IN SOCIAL SUPPORT NETWORKS OF THE PEOPLE
WITH MOTORIC DIFFICULTIES IN SLOVENIA

Mateja Nagode and Polona Dremelj are professional assistants of the Republic of Slovenia Institute for Social Protection.

When people are confronted with problems and stress, they usually turn for help and social support to friends, families, or partners. Social support is understood as a complex concept of a higher order. The presented features of social support networks of the people with motoric difficulties in Slovenia are based upon a research of social support networks in Slovenia, which was carried out in 2002 by the Centre of methodology and informatics at University of Ljubljana Faculty of Social Studies and the Republic of Slovenia Institute for Social Protection. The findings based on a representative sample for the age 18 years or more show that approximately 10 percent of the adult population in Slovenia has motoric difficulties, amongst whom there are more women (58 percent). The differences in social support networks for men and women with motoric difficulties are visible in the network structure: the women's networks include more relatives, while the men's networks include more friends, co-workers, and neighbours. The crucial source of emotional support and support in case of illness are for men their partners, and for women their children.

Keywords: social support, social networks, gender differences.