

PROBLEMS OF PERSONS WITH INBORN GENDER IDENTITY DISORDER SYNDROME – SOCIOLOGICAL ASPECTS

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ABSTRACT

The paper focuses on some problems (medical, social, legal) faced by persons with Inborn Gender Identity Disorder Syndrome (IGIDS). The so-called “transsexualism” is a huge problem for persons who “hit the wall” in fulfilling social roles consistent with the perceived gender. It has to be underlined that the social functioning of these persons is extremely difficult, because disapproval of the phenotype/somatic sex hinders their self-fulfilment. The article is based, partly, on the analysis of data from 600 cases of persons with IGIDS who are the patients of one of the co-writer and on the literature of the subject. The main objective of the paper is to point at an important social problem, which is far from achieving an optimum solution. Raising public awareness of the problem is the main motivation of the authors of the paper.

***Keywords:** perceived gender, assigned sex, sex identity/identification, gender recognition, gender reconciliation/reassignment*

INTRODUCTION

There is no doubt that persons with IGIDS encounter various difficulties in their lives. These problems are often very complex and interlinked and, what is more, they give such persons a feeling of great discomfort [1]. For such person values such as: life self-fulfilment, achieving satisfaction from social roles, experiencing the fullness of life is extremely difficult to achieve. At the root of any difficulties lies the discrepancy between the assigned (registered at birth) sex and the perceived (brain) sex. This discord is difficult to realize by the individual who feels it (mentalisation problem), and also difficult to diagnose by a medical specialist (lack of a well-established algorithm of management). Difficulties in establishing one's own sexual identity can lead to depressive states and even to suicidal thoughts and attempts (more than 40 percent of respondents to the survey). It should be stressed that this percentage is higher the lower the acceptance of the environment and the support (assistance) provided by the people close to them.

The disapproval of phenotypic sex, which is faced individually, has its social contexts, and these certainly include relations with the closest family members. A strong misunderstanding of the problems of people with IGIDS and the ostracism shown by family and immediate environment are factors that increase the risk of suicide attempts. Particular attention should be paid to relations with parents, especially when gender identity problems affect minors who cannot legally decide for themselves. The complicated and unregulated way of legislative proceedings concerning changes to the birth records is another problem for persons with the desire to reconcile the assigned sex with the sex they feel. These and other problems should be reviewed and their frequency should be verified in order to minimize as much as possible the social barriers and disadvantages faced by persons with IGIDS. On the one hand, it is a task for sociologists, researchers of the social world, but also for decision-makers, politicians and publicists who disseminate specific images of people with IGIDS in human consciousness, and finally for teachers and educators. Raising awareness of the problems of persons with IGIDS and disseminating knowledge about the real determinants of this disorder may contribute to a better understanding of these persons and reduce their social marginalisation.

REMARKS IN THE MEDICAL CONTEXT

There are several sources of problems related to medical management. The importance of early diagnosis of the disorder is usually emphasized, as in such a case the pharmacological process of sex reconciliation brings better results. This is in line with the recommendations made by the WPATH (World Professional Association for Transgender Health) Committee of Experts [2]. The issue of early diagnosis should therefore be highlighted. Unfortunately, it is difficult because no clinical marker of this disorder has been developed so far. Moreover, there is also a lack of standards for diagnostic procedures. This is related to the frequently occurring pushing back (downplaying) of the problem by parents, who are unaware of the real psychological dilemmas of their child may contribute to the delay in obtaining the right diagnosis and taking appropriate hormonal treatment. It is important to mention the huge role that the first IGIDS specialists – psychologists, psychiatrists, medical doctors, sexologists – can play here. Due to the lack of methodological standards in these disciplines, the importance of knowledge and experience of specialists, who are relatively few in Poland, is growing. In particular, the access to child psychiatrists is difficult in Poland because there is a lack of specialists in this field. Preparation for work with people with IGIDS is not a separate topic in education during medical studies, and many doctors do not undertake diagnostics and treatment, considering them to be too risky. The seriousness of this problem is raised by the fact that there is still a need to look for methods to allow early and objective confirmation of this disorder. It should be taken into account that according to a study published three years ago, about 30 percent of cases in children are confirmed as a permanent feature of sex disapproval [3]. The early signs of this disorder cannot, on the one hand, be ignored and, on the other, must be reliably verified. Only then do the chances for

a good diagnosis and the right treatment increase, and thus the chances of achieving optimal results.

The diagnosis of IGIDS is based on the detecting of following features:

- the clinical incompatibility between the psychological sense of sex and morphological and biological structure, confirmed without any doubt through doubt clinical and laboratory tests, and social sex,

- fulfilling social roles compatible with the mental perception of the sex, incompatible with bodily features,
- irresistible and permanent desire to be a woman or a man, depending on the actual situation, which is reflected in the way people dress and behave,
- aversion to the anatomical structures of the biological sex and the resulting constant striving to carry out corrective plastic surgery of external sex traits by complicated surgical procedures,
- the presence of a sense of great suffering with suicidal thoughts and attempts, also when sex reconciliation expectations of a person with IGIDS are not met [4].

The diagnosis already uses fMRI tests, which can show sex differences within the structures of the white substance in the brain. This is a certain indication to help qualifying a person for taking up hormone therapy. Diagnostic hopes are also related with the development of fMRI scan on sex differences in response to pheromones and specific sexual stimuli. It should be stressed, however, that the availability of this test in Poland is negligible. Moreover, the very high cost of this method makes it almost impossible to use it for early diagnosis of persons with IGIDS. Therefore, the only diagnostic method so far is to state the consistent aspiration of a person to fully reconcile on the sex of the body with the one being felt. It must be supported by a thorough psychological opinion confirming this full and constant determination to agree on gender. Beforehand, however, mental illnesses requiring treatment should be excluded, and these can only be ruled out by a psychiatrist. In fact, IGIDS persons are strongly striving to implement the “program of being oneself”, often against the environment, the persons from the closest environment and even against the will of the parent(s). However, in view of the difficulties already identified, the definitive determination of such an aspiration must be based primarily on the patient's subjective declarations.

The human sexual developmental disorder referred to as IGIDS has so far been classified as “transsexualism” by the ICD-10 (in force since 1996). According to the ICD-11, this is not a mental disorder, which is intended to make it easier for persons with IGIDS to reconcile the sexes according to their perceived one. At this point, we should also mention the right postulates of depsychiatrisation and depsychologisation of the problem (European Parliament resolution of 28 September 2011) [5]. However, the extended postulate of demedicalization of this developmental disorder, promoted by LGBT circles, is not justified. Medical care for persons with IGIDS is necessary throughout their

lives (it starts with their first visit to the doctor, but a continuous hormonal supplementation is required to maintain their well-being). The psychotherapeutic significance of the rapid start of hormonal therapy cannot be overestimated. This is because the patient comes to the first visit usually under a lot of stress, often strongly determined to take steps to give his/her life the right shape. Laboratory blood tests are required to determine the hormonal sex. It is also necessary to assess the overall health status in order to exclude any risk arising from the expected long-term use of chemical agents (hormonal action). As confirmed by research, the vast majority of patients experience a decrease in the tension associated with dissonance in terms of sex identity after starting hormone therapy. Their general well-being is improving. Patients must be aware, however, that the subsequent steps of sex reconciliation (removal of gonads) cause the loss of reproductive functions. Further therapeutic management is a periodic check-up. Verification of both health status and progress in demasculinisation and feminisation or defeminisation and masculinisation (depending on the doses of hormonal preparations used) is carried out. Once again, it should be emphasized that the effects of hormone therapy depend to a large extent on the start of administration of the preparations in relation to the developmental age of the individual.

PROBLEMS OF PERSONS WITH IGIDS IN SOCIOLOGICAL TERMS

Sociological studies of persons with IGIDS focus on several research fields [6]. These include issues such as: the body and its functions in social space, social gender roles determining the framework for specific behaviours, the process of constructing individual identity, the functioning of people with IGIDS (individual and in support groups), marginalisation and stigmatisation processes, quality of life and others. A comprehensive and representative empirical study of persons with IGIDS is difficult to conduct due to methodological and ethical considerations [7]. Persons with IGIDS at different moments of their lives determine their situation ambiguously. It depends on the advancement of the problem mentalisation process, entering a path to its resolution (starting the treatment and its duration) or the quality of life that these persons lead after the surgical sex reconciliation. The latter is the culminating point on the way to achieving the desired shape of one's own carnality. The desire to achieve this state reinforces the desire to bring the body as close as possible to the felt sex by means of surgical procedures or hormonal treatment [8].

It should be noted that the different gender patterns of social behaviour displayed by people with IGIDS are significant for them from the point of view of establishing themselves in a specific sense of sex identity. At the same time, they are not in line with social models, which leads to misunderstanding and lack of social acceptance. The basic problem is, as mentioned above, the mentalisation (awareness) of this disorder. Cognitive dissonance related to perceived and assigned gender becomes an individual's sensation (experience) that is difficult to

name and verbalize. The difficulty is due to the fact that this discrepancy is perceived as incomprehensible (unnamed) and at the same time painful. In early childhood, the demonstration of this difference can be more “natural” and spontaneous. However, the problems increase as one enters adolescence [9]. Then the mental and bodily changes characteristic for this period intensify, which may strongly disturb the image of oneself and one's own carnality. Uncertain or increasingly unacceptable image of one's own body becomes problematic for an individual and hinders his or her everyday existence [10]. It is clear from the research in which respondents emphasize problems in functioning in peer groups, communication difficulties in relations with relatives, increasing feeling of frustration and depressive moods.

Taking action to reconcile the sex involves further problems: obtaining approval from parents (caregivers), their consent necessary for treatment, and legal action. It is not easy to make parents aware (or convince them) of their own feelings about gender, especially if they do not notice the problem or ignore it as the one raising anxiety in them. It is very important for children and teenagers to operate in peer groups (school, friends, play groups). Meanwhile, gaining understanding and acceptance of one's own feelings by the environment can be of great importance to a person who has doubts about his or her gender identity. Their lack, however, increases discomfort and sentences a person with IGIDS to loneliness and exclusion. More than half of the respondents indicated that their loved ones were not aware of the seriousness of the problem they were facing. This is a clear indicator of the extent to which ignorance of the nature of the disorder is widespread. It is often classified as a temporary mental disorder, which does not necessarily have to be confirmed in a specific case. The most disadvantageous situation for a person with IGIDS is when parents consistently ignore the problem. Failing to help, they act against, because they delay the start of diagnostic procedures and treatment. This is an extremely difficult situation, because a person with IGIDS remains alone with his or her problem. Having a strong desire to regulate his or her life, even against the will of the family, he or she can take appropriate steps only becoming an adult under the law (in Poland it is the age of 18 years) [11]. In such cases, however, young people usually do not have financial independence, which does not allow them for full autonomy of decisions. This may become a further element deepening the alienation of a person with IGIDS, leading to depression or even suicide attempts.

It should be stressed, however, that even with the support of the immediate environment (family, friends), the widespread ignorance of the IGIDS problem causes that these persons face many difficulties in everyday life. Attempts to behave and social practices according to perceived gender are most likely to cause negative reactions in the environment because the it perceives these behaviours as incompatible with accepted cultural patterns. They are rooted in universally recognized binary gender division and culturally defined role-playing patterns. This is the case with external signs of gender identification, which serve to emphasize the features of the felt sex – clothes, hairstyle, makeup. The medical

problems outlined in the first part of the text do not disappear with the stage of making the decision to launch procedures aimed at sex reconciliation. Deficiencies in the medical staff are visible already at the moment of choosing the right psychologist and specialist doctor. Therapeutic problems may also include the lack of financial reimbursement from the National Health Fund (NFZ) for tests and some drugs necessary in the process of sex reconciliation. The lack of a developed algorithm for diagnostic management in this type of disorder causes few doctors in Poland to undertake diagnostic and therapeutic management. This makes the access a specialist doctor even more difficult.

Problems on the part of the inefficient health system (and its staff, so the doctors) and patients' expectations overlap. Persons with IGIDS expect visible changes and similarity to the sex experienced after the use of hormonal drugs. Doctors, on the other hand, see this as a particular challenge and risk, since their diagnosis is based only on the defining the degree of determination of the patient to reconcile his or her sex. The subjective declaration of the appropriate therapy is the starting point for the next steps. It should also be noted that the health system in Poland is not flexible enough to reimburse diagnostic procedures, tests and medicines. All this influences the duration of the procedures that allow a person with IGIDS to reach the desired state. Collecting the required documents (psychological and psychiatric opinion) means additional time and related costs. During the diagnostic and therapeutic process, conditions are set for the legal acceptance of the change of sex information in the birth certificate (sex registered at birth). It is only the court's change of the provision that is the basis for obtaining relevant documents. Those that correspond to the perceived sex and allow you to function in accordance with who one feels. Court proceedings take place, in accordance with Polish legislation, at the request of a person with IGIDS. This fact does not raise any objections; however, the lawsuit is directed against parents, which may additionally cause tension in family relations. From a formal point of view, a very difficult psychological situation arises; a child (of adult age) acts against his or her parents in order to become what he or she really feels.

The change in the record of the birth certificate is a milestone in the sex reconciliation process. It allows for further efforts and actions in the field of surgical treatment. There are several medical centers in Poland that perform such surgeries, but so far no centre has been established that would provide comprehensive care and guidance until optimal results are obtained in terms of bodily matter. Surgical procedures and creation and plastic surgeries are relatively expensive and, in most cases, burden the budget of a person with IGIDS or his or her family. Subjective self-determination can also be limited for economic reasons. The surgery is sometimes postponed, which adversely affects the quality of life of persons with IGIDS and their full sense of sex identity. Without financial support from the family, a young person is not able to finance these procedures on his or her own. It should be stressed here that the claim put forward by WPATH is a resignation from the Real-Life Test for diagnostic purposes [2]. It prolongs the diagnostic stage and sentences a person with IGIDS to additional problems of

not only financial nature. This claim, however correct, is not applicable in Poland and it is so for economic reasons. Reduction of the diagnostic time in order to obtain better results of the therapeutic process is not only impossible in Poland, but the financial factor considerably prolongs the duration of the procedure. According to statistics, the whole procedure lasts on average from a few to several months. Unfortunately, sometimes it is also counted in years [12]. Developing aesthetic surgery, on the one hand, meets the needs of persons with IGIDS. However, its availability is very limited due to high costs.

The problems mentioned above have a negative impact on the quality of life of persons with IGIDS. They also lower the autonomous actions of individuals, negatively affect the subjective self-determination and decision making regarding the shape of one's own biography. These difficulties are already visible at the school (educational) level and may be exacerbated in terms of realization of professional aspirations, self-fulfilment in family roles and achievement of the desired social status.

CONCLUSION

Although IGIDS is a bioconditioned developmental disorder, the difficulties encountered by persons with IGIDS in their lives are to a large extent socially generated. They result mainly from low awareness of the problem, little knowledge about its essence, misunderstanding of the needs of persons with IGIDS, duplication of stereotypical, prejudiced opinions and lack of sensitivity to other people's problems. Socially established mechanisms relate, for example, to the reception of culturally produced gender-specific behavioural patterns. This means that the behaviour of persons with IGIDS in accordance with perceived sex is interpreted by the environment as non-standard (incompatible with the assigned sex). However, an adequate level of knowledge and social sensitivity could counteract situations where persons with IGIDS are at risk of marginalisation or even discrimination. It also seems justified to call for the establishment and introduction of uniform diagnostic and therapeutic standards. From a sociological point of view, it is extremely important to identify the real problems of persons with IGIDS functioning. The already mentioned research fields (identity, carnality, support groups, life biographies, social statuses of persons with IGIDS) offer many cognitive possibilities. As far as social practice is concerned, the necessity of creating institutional forms of assistance for persons with this developmental disorder and the educational (awareness-raising) aspect of the phenomenon in question is emphasized. Comprehensive activities, including social and medical ones, could contribute to improving their functioning in society.

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