Deinstitutionalization

of selected services for people with disabilities in Poland

- a sociology of knowledge perspective

(summary)

This paper is devoted to the issue of the discourse built around the process of deinstitutionalization of social services for people with disabilities by social actors embedded in the perspective of the medical and social (extended to human-rights) model of disability. The perspective adopted is the sociology of knowledge as presented by Karl Mannheim in his work *Ideology and Utopia*. A phenomenological perspective and the sociology of knowledge approach to discourse (SKAD) derived from it have been used helpfully.

Deinstitutionalization is understood as the process of transition from institutional support for people with disabilities, based on places of collective residence, to community-based support. The analysis is focused on two leading instruments of deinstitutionalization: sheltered/assisted housing and personal assistance for people with disabilities.

In terms of the Mannheimian perspective, the leading ideology was identified with the assumptions of the medical model of disability, while the contesting utopia with the concept of the social and human-rights model. The supporters of *ideology* and *utopia* were conventionally named – conservatives and reformers, respectively. These terms, like *ideology* and *utopia*, as Mannheim intended, are neutral in nature and describe the sets of thoughts used by different groups, without valuing them.

Among the parties forming the discourses of deinstitutionalization, groups with specific, often distinct, experiences of disability constituting their conditions of existence were singled out. The experience of disability was framed as direct (people with disabilities) and indirect (families of people with disabilities, employees of support institutions, decision-makers who build and implement social policy, and allies of people with disabilities). Access to power, understood as the ability to influence the formation and execution of social policy, was taken into account as an additional factor.

For the purposes of the analysis, Mannheim's method – understood as a research procedure that allows for the analysis of public discourse – derived from *Ideology and Utopia*,

1

was reconstructed. The analysis was based on texts reflecting discourses created by parties and groups in the years 2012 (ratification of the UN Convention on the Rights of Persons with Disabilities) – 2022 (adoption of the Polish Strategy for the Development of Social Services). Texts created by different types of experts (understood here broadly – as having different experiences of disability and power) were considered. They are the products of both group arrangements (multi-author texts, created by institutions) and the result of the involvement of individuals representing (or cooperating with) various governmental, local governmental and non-governmental institutions.

The analysis is divided into two stages. In the first, theoretical one, the "perspectives" (*Aspektstruktur*) of the sites – understood as Weberian "ideal types" – characterizing their model of thought were constructed. The perspectives include such elements as the ontology of disability, the dominant models of thought, the structure of the categorical apparatus, the meaning of the concepts being used, the phenomenon of the counter-concepts, the absence of certain concepts, and the level of abstractness. The conditions of existence of the groups are also described, with reference to their experience of disability situated within the socio-historical context of the deinstitutionalization of disability.

The second stage is an empirical analysis. It concerns the confrontation of the description built in the theoretical part with the results of the textual analysis. The phenomenological structure of the groups, based on the SKAD assumptions, was also analyzed. Here were taken into account such issues as: the problems of deinstitutionalization pointed out by the parties (their causes, solutions, responsibility of the groups); the positioning of the parties – understood as the positioning and perception of themselves and others; the model of the culture of things/wealth; the values emphasized by the parties. The analysis also dealt with the lexical choices used by the parties as a characteristic of their thinking styles.

The method of imputation based on the principles of relationism and particularization was also considered, as postulated by Mannheim. The first principle is concerned with indicating the relationship of a set of thoughts (and with its various types of statements) to its author, who is embedded in a specific structure and historical time. The second principle concerns the possibility of determining the validity of an utterance only in connection with the perspective (understood as a point of view) of a particular party or group. Thus, in accordance with Mannheim's assumptions, it is possible to decide on the validity ("truthfulness") of an utterance only with reference to its context and the specific model of thought embedded in it, without reference to its absolute sense.

The paper also reflects on communication between the parties. Its starting point is, indicated by Mannheim, the phenomenon of "talking past one another". It consists in referring to the statements of the other party, without noticing the dissimilarity and different conditions of existence of the adversaries, which determines the impossibility of real communication.

An analysis of the parties' perspectives revealed their dominant models of thought, divided into a conservative faction – guarding the current system of support for people with disabilities based on an approach to disability starting from the assumptions of the medical model (understood as the leading *ideology*), and a *reformist* faction – contesting this way of thinking, seeking solutions based on a social and human-right model of disability (understood as *utopia*). For the conservative side, the starting point in thinking about disability is related to impairment and the need to secure it, while the reformist side shifts the focus to considering disability as a socially generated phenomenon and perceives people with disabilities as human rights holders in the first place.

Starting from different ontologies of disability leads the parties to understand the concept of deinstitutionalization in different ways, even though both agree on the need to implement it, and start from the overriding value of the well-being of people with disabilities. Conservative thought emphasizes the need to gradually introduce elements of deinstitutionalization (such as personal assistance for people with disabilities and sheltered/assisted housing) but without abrupt modifications to the existing system. This leads to calls for the preservation of collective housing facilities - while seeking a new formula, which is seen as reducing their size and giving them new functions. Deinstitutionalization in this view is based on the category of "care" for people with disabilities and is one of the possible options for support (complementary to the institutionalized system). At the same time, the strengthening of family support is advocated as an important factor in allowing people with disabilities to remain in their local communities. Reformist thought emphasizes the community nature of deinstitutionalization based on the category of "support" for people with disabilities in local communities. It is presented as a program for the protection and realization of human rights of a systemic (permanent) nature through the organization of support through two leading instruments: personal assistance and sheltered/assisted housing).

An analysis of the parties' categorical apparatus made it possible to identify certain strategies they use in communicating about deinstitutionalization. For the conservative side, the following were identified: the strategy of attaching utopian elements to their own discourse; the strategy of adopting utopian concepts; and argumentative strategies such as arguing for the inevitability of preserving institutions of collective residence, presenting deinstitutionalization as a process that is difficult to implement and requires prudent, evolutionary measures. The reformist side uses strategies such as: the strategy of deprecating institutions pointing to their inefficiency and systemic "doom to failure" as "total" institutions; the strategy of "making" deinstitutionalization real, showing the possibilities of its implementation. A separate strategy of the reformist side is the conciliation strategy, which consists of moving away from the categorical call for the liquidation of institutions to emphasizing the need to increase support in local communities.

The analysis revealed the characteristic counter-concepts used by the parties (conservatives and reformers, respectively): care-support; and dependency-independence (independent living). At the same time, as an overlooked (or: heavily restricted) element of the discourse by both sides are issues related to intellectual disability as potentially one of the most difficult in the context of deinstitutionalization.

The analysis of the elements of the phenomenological structure mainly refers to the relationship between the parties and their perception of each other, as well as their positioning of themselves. The conservative side perceives the deinstitutionalization process itself in the category of a problem to be solved, which relates to the lack of infrastructure, costs and the difficult situation in the labour market (staff shortages in the helping professions). The reformist side, on the other hand, considers the existence and further development of the existing system of collective housing facilities, as well as the too slow efforts to deinstitutionalize it as the main problem. At the same time, both sides recognize the problem of the lack of support for families in local communities. The reformers also agree with the comments of the conservative side regarding the lack of infrastructure and the difficult labour market of the helping professions. The solution to the problem, from the conservative side's point of view, is prudent and gradual reform of facility support. The reformers, on the other hand, expect relatively rapid changes leading not so much to reform as to systemic change. Both sides see the need for responsibility for the deinstitutionalization project to be borne by both government and local government circles, as well as the social side.

The conservative side (epitomized in particular by policymakers) sees itself as guarding the stability of social policy and the resulting support system of which it is the architect. Its sense of responsibility for decisions leads it to consider demands for change cautiously and over a long period of time, dictated largely by concerns about the inability to safeguard people with disabilities in the event of rapid deinstitutionalization. The reformist side sees itself as an engine of change, and at the same time the guardian of the Convention on the Rights of Persons with Disabilities and the resulting demand for the protection of human rights. In mutual communication, the reformist side accuses its adversaries of failing to understand the concept of deinstitutionalization and adopting a strategy of posturing to implement it, as well as failing to coordinate efforts. At the same time, it raises the marginalization of reformist thought by conservatives and the removal of the social side from partner discussion and influence on key decisions. The conservative side sees opponents as a kind of aggressor, postulating the destruction of the existing system, lacking coherent and concrete proposals for change, operating with vague slogans, and avoiding deeper reflection on the costs and complexity of the deinstitutionalization process.

The analysis reveals a link between conditions of existence and the point of view taken by both sides. Both the experience of disability (direct or indirect) and access to power (and related responsibility) proved to be important here. In this context, the division between the conservative side and the reformist side is drawn on the line between decision-makers (government side) and the social side (NGOs). The parties, focusing, on presenting their rationale and criticizing the rationale of the opposing side, very rarely refer to the social and living situation of their adversaries. The phenomenon of "talking past one another" is characteristic of communication between parties and is dictated by the need to maintain the coherence of their own discourse. At the same time, it should be noted that the parties' discourses are subject to mutual contamination and hybridization. The concepts they use intermingle, are borrowed, and lexical choices in many cases indicate the operation of the other party's thought resources. This is a result of the meeting of discourses as well as due to the lack of full crystallization of thought assemblies, as well as the instrumental approach to discourse in order to obtain certain benefits.

The analysis presented here is macro in nature, which means that at its level it was only possible to demonstrate the general, basic opposition of *ideology* and *utopia*. On the other hand, the complexity and inter-penetration of the parties and the groups operating within them, as well as their complicated (often ambiguous) social situation, translating into the shape of the discourse they produce, is already apparent at this stage, which should be subjected to further micro-analysis. The phenomenon of " talking past one another " also requires in-depth research, along with a search for those moments where the parties "talk to one another." Among the research demands are also analyses of: group processes of the social construction of reality – concepts and postulates related to deinstitutionalization; the impact of models of thought on the social situation of groups (thus, the direction opposite to that presented in this work); the mythologization processes to which deinstitutionalization is subjected in the thought of various groups. A separate demand is to extend the study of the ideologies and utopias formatted here

beyond the issue of deinstitutionalization, which is only a slice of the dispute between different perspectives on disability perception.

The functioning of the parties in conditions of conflict, with the absence of "talking to one another" and the formation of ad hoc alliances (including at the discursive level) leads to the conclusion that deinstitutionalization is an endeavour that will never be finally closed. The parties' separate sets of thoughts, based on different understandings of the same concepts, as well as their own conceptual grids, do not allow them to communicate effectively, and thus to take steps towards the commonality of the deinstitutionalization project. The work presented here, starting from Mannheim's thought and the concept of mediating discourse analysis based on it, aims not only to characterize the parties' thought teams but also to draw attention to the need to change communication between them. The postulate of mediating work involves the role of the researcher as the initiator of such work, the result of which is to be the translatability of the parties' perspectives. The latter is understood as enabling the parties to understand each other's points of view, rather than commodifying them or adopting the other party's perspective. The study presented here, therefore, is of a mediating nature, and its final demand is to call on the parties to undertake mediating work that could provide conditions for opening a debate about the quality and manner of communication between them.

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