

The infantilization of intellectual disability and political inclusion: a pedagogical approach

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Abstract

The present paper looks at the way in which political and scientific frameworks, as well as everyday life dynamics work to exclude people living with intellectual disability (ID) in Romania from political life and how these dynamics could be overcome through crafting communicative-dialogic pedagogical interventions geared at political inclusion. I argue that the political exclusion of people with ID is built into the formal political order, as well as doubled by a twofold infantilizing dynamic. On the one hand, the scientific and academic psycho-pedagogical discourse still operates with classifications that inscribe people with ID with chronological “normal” ages inferior to their biological age. Their subject position is thus “fixed” at an age below the voting limited. This move is seconded by the way in which (formerly) institutionalized people with ID are referred to as “children” (despite their fully adult ages) in a small (post)institutional town, as well as in other care settings that I have explored ethnographically. Finally, the paper explores the stepping stones of alternative interventions, built on a communicative-dialogic methodology for politically including people with ID that could work to overcome the infantilizing dynamics.

Keywords: intellectual disability; CRPD; depoliticization; inclusion; infantilization.

1. The political context for people with intellectual disabilities (ID) in Romania

Recently, the equal political inclusion of people with disabilities has been legally enshrined in Romania’s 2010 ratification of the UN Convention for the Rights of People with Disabilities, Article 29⁶. Yet, both before and after this symbolic political act, the recognition of actions of people with intellectual disabilities as politically relevant has been limited to a small number of people in contact with self-advocacy groups.

The widespread political discrediting of people with ID is connected to a common everyday and “scientific” problem – that of seeing people with ID as intellectually and

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⁶See Article 29 of the Convention, available here <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-29-participation-in-political-and-public-life.html> accessed on 27.01.2019

politically immature or more plastically and plainly as children. As we will see in the following, different forms of infantilization operate in the Romanian context, both on an academic and scientific level, as well as in the everyday life of (post)institutional care contexts. These infantilizing dynamics serve to consolidate and widen the already legally enshrined dynamics of political exclusion.

The Romanian Constitution still restricts the right to vote for people deemed incapable by a court order, explicitly on the grounds of mental disabilities, art 36, paragraph 2: “The mentally deficient or alienated persons, laid under interdiction, as well as the persons disenfranchised by a final decision of the court cannot vote.”⁷ The vote restriction itself is not an exceptional one in European terms, since Romania is one of many European countries with such a provision (alongside Bulgaria, Germany and Portugal among others)⁸. Nevertheless, as has been remarked by the CRPD committee (report on Hungary CRPD, 2012), the restriction of this right is not in line with Article 29 of the CRPD.

Yet, the way in which it is worded is also worrying because of the ableist (offensive way of referring to people with disabilities) formulation of the de facto restriction to vote of legally incapacitated people with mental disabilities. Moreover, the enshrining of de facto political exclusion in the Constitution makes it even more difficult to change through a political process that would bring Romanian legislation in line with the CRPD.

Nevertheless, these formal limits to participation still refer to a minority of people with ID, whereas, as I will argue in the following, infantilizing dynamics affect close to everyone living with ID in Romania. Since a “child” cannot be seen as a full political actor (for example voting is conditional upon reaching the age limit 18), challenging the way in which infantilizing dynamics operate is paramount to establishing a discursive climate in which people with ID are recognized as equal conversation partners, and thus as political actors in their own right.

⁷ „Nu au drept de vot debilii sau alienații mintal, puși sub interdicție, și nici persoanele condamnate, prin hotărâre judecătorească definitivă, la pierderea drepturilor electorale.”, full text of the Romanian constitution available here http://www.cdep.ro/pls/dic/site.page?den=act2_1&par1=2#t2c2s0sba36 (in Romanian), in English http://www.cdep.ro/pls/dic/site.page?den=act2_2&par1=2#t2c2s0sba36 accessed on 27.01.2019

⁸ See the graphic illustration provided by the European Agency for Fundamental Rights, available at <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/legal-capacity> accessed on 27.01.2019

Such challenges have been brought forward by disability self-advocacy groups, especially *Ceva de Spus* (Something to Say), a self-advocacy group of people with disabilities including ID in Timișoara⁹. The group has gained local and national visibility, as well as was involved in European policy making processes through the European Disability Forum. Nevertheless, both their visibility and impact could be aided by overcoming the infantilizing dynamics that limit their recognition. Moreover, the more open interventionist methodology that I propose at the end of the paper might aid self-advocacy groups in extending their political activities and membership base.

2. Infantilization of people with ID as classificatory science

Three introductory works to the discipline of special education or psycho-pedagogy (Verza, 2002, Gherghuț, Frumos & Raus, 2016 and Roșan (ed), 2015) can be seen as highly influential in the Romanian context of practice, since their authors are connected to and teach at three of the largest academic centers in Romania (Bucharest, Iași and Cluj). All three works introduce classificatory systems for diagnosing people with intellectual disability¹⁰.

Two of the three works (Verza, 2002, pg. 47f and Gherghuț, Frumos & Raus, 2016, 26f.) use a classification of intellectual disability that can be considered infantilizing. Whereas Verza (2002) looks at the severity of intellectual handicap, Gherghuț, Frumos & Raus (2016) term the condition “intellectual deficiency”. Nevertheless, both works introduce the different degrees of what could be likened to an understanding of intellectual disability as something strictly pertaining to an individual, based on the assessed person’s IQ. The diagnostic categories vary only slightly, the conditions proposed are: liminal intellect (IQ 70/75 – 80/85 or 80-85/90), which is considered to be bordering the condition of “normality” (compare Verza, 2002, pg. 49f.); followed by the three degrees of deficiency, which are relevant to my analysis.

The 1st degree mental deficiency (IQ 50/55 - 70/85) is considered by the authors to be corresponding to “the normal development at a chronological age between 7-12 years” (Verza, 2002, pg. 50) and corresponding to the “operational thought mechanisms of the

⁹<http://www.cevadespus.ro> accessed on 27.01.2019

¹⁰Although the cited works do not all use the term disability, for coherence reasons I will continue using it throughout the text, signaling when it differs from the authors’ I am quoting use.

specific mental age of 7-9 years” (Gherghuț, Frumos & Raus, 2016, pg. 27). Similarly, age ranges are provided for 2nd degree mental deficiency (IQ 20-50) and ages ranging from 3 - 7 years (Verza, 2002, pg. 56) and 2 - 7/8 years (Gherghuț, Frumos & Raus, 2016, pg. 28) and 3rd degree mental deficiency with an IQ under 20 and an age of up to 3 (Verza, 2002, pg. 59) or 2 (Gherghuț, Frumos & Raus, 2016, pg. 30) years of age.

This classificatory system¹¹ might be useful, since it includes information related to the likely abilities the person will have, as well as the areas in which a different form (understood strictly as degree, so in a simple progressive manner by the authors) of development can be expected. Nevertheless, what is problematic about the way in which the classification is presented is not only the progressive degrees of development (and not areas of development) considered relevant for assessing the person’s abilities, but also the fact that those scoring less on IQ tests are likened automatically to children of different ages. The political consequence of this discursive move is easy to anticipate, people are considered child-like, therefore politically immature and de facto incapable of autonomous decision making. Taking the diagnostic classifications at face value would involve considering people with lower IQ scores automatically as “underdeveloped” in all fields of life.

The underlying position has changed professionally on an internationally relevant level: the shift from IQ-based identification of intellectual disability to a more complex one, based on a person’s abilities to “function” in different fields of life (conceptual, social and practical) is documented in the current *Diagnosics and Statistical Manual of Mental Disorders - DSM 5* (American Psychiatric Association, 2013, pg. 33f.). This more complex view does not have indirect discursive implications in terms of infantilization and has also travelled into the Romanian scientific and academic context (see Roșan & Bălan-Baconschi, 2015, pg. 104f.).

3. The Infantilization of people with ID in everyday life

¹¹ I choose to read it as a single system despite the small variations of content between the two works.

The following section is based on one year of ethnographic research conducted in 2015 in several locations in the northeast of Romania, surrounding current and former institutional care settings for people with ID and/or suffering from mental illness.

Many people, who are still currently in the residential care system for people with disabilities, also grew up in a care institution for children, and often came to live in a residential institution for adults upon reaching 18 years of age. The people who I met during my fieldwork had grown up in the “system”¹² as a consequence of the pronatalist decree (decree 770/1966¹³), and the legislation supporting the institutionalization of poor and disabled children (especially law 3/1970¹⁴) during the early years of Ceaușescu in office. Such people would often be referred to as “children”, even though the people I had come to meet were in 2015 generally older than 25 years of age.

The fact that they were called “children”, thus, had nothing to do with their age. Nor were all the residents and former residents of residential institutions for the mentally ill and disabled called “children” – the label only applied to those people who had grown up in the system after being abandoned at birth or in the first life-years. People who had spent their childhood and early adulthood outside of institutions, and had come to be given into state care as a result of mental illness or difficulties subsisting on the outside, were never referred to as “children”. Moreover, in one of the neuropsychiatric institutions that I spent several weeks observing, they were referred to as the “adults” – the contrasting term to “children”.

I encountered an even more interesting situation, in another setting that I explored for several months, where some people with ID that had grown up at a neuropsychiatric children’s hospital had been part of a complex program of deinstitutionalization preparing them for independent living, whereas others had not. The members of the first group were referred to as “the young people”, and members of the second group were commonly referred to as “the children”. This was the case even though the “young people” were generally much younger than the “children”. The humanitarian organization had insisted on integrating young people in their program in the late 1990s, so at the time of my fieldwork

¹² Growing up in the “system”

¹³ <http://www.legex.ro/Decretul-770-1966-363.aspx> accessed on 27.01.2019

¹⁴ Legea 3 pe 1970, available here <https://lege5.ro/Gratuit/gu4tmobu/legea-nr-3-1970-privind-regimul-ocrotirii-unor-categorii-de-minori> accessed on 27.01.2019, the law was substantially changed by government decree in 1997.

the “young people” were aged twenty three to over forty. The “children” had been transferred to an adult institution after the closing of a children’s institution in 2001, time at which they were at least 18 years of age. In 2015, “the children” were thus at least 32 years old, generally around 10 years older than the “young people”. The label “children”/ “copii” was often used to explain why people couldn’t do or understand something. Moreover, it was never used to describe people who had grown up at an institution, but were engaged in regular employment and were living on their own.

In both care contexts, the neuropsychiatric institution with the “children” and “adults”, and the after-life of the children neuropsychiatric hospital with the “children” and “young people”, the “children” themselves would refer to themselves and each other as “children”. This was done especially when stressing vulnerability or need, and when asking for a gesture of compassion or generosity. This is emblematic for the asymmetric relationships that were built into the social order in which they were socialized – the subject position of “children” was a fruitful one for asking for things, but not for claiming rights, a position reserved to those understood as full citizens. Thus infantilization served to depoliticize “children”, by placing them in an implicitly inferior subject position, that nevertheless allowed to voice claims as requests to more powerful others¹⁵.

4. The potential of re-politicizing ID through communicative and dialogic pedagogical interventions

Although the two forms of infantilization operate on different levels, the scientific and the everyday life of care settings, they are nevertheless entangled in practice. People with ID are understood as “children” both by the academically trained professionals they interact with, as well as by the care settings and their local surroundings, thus making “eternal childhood” an almost inescapable everyday reality. While the individual way out of this situation is through attaining personal independence in terms of having employment, a place to live, one’s own social networks, this is not an immediate possibility for all people with ID that are pejoratively understood and come to understand themselves as children.

¹⁵Since both research settings had been deeply transformed by the transnational humanitarian practices of the 1990s, it is obvious that the humanitarian power asymmetry shaped these relations as well, a point that I will not explore further at this stage.

Infantilization thus comes to normalize the political exclusion of people with ID in a manner that needs to be challenged. Instead of thinking in terms of infantilizing the individuals with ID, an alternative mode of intervention based on the social model of disability would be to create political participation mechanisms that rework the political space in an emancipatory way. This is both a question of taking people with ID seriously as political actors and “experts through experience”, as much as it is a question of designing pedagogical interventions that can make substantial political participation possible.

This is the case, since previous research has shown (Redley & Weinberg, 2007) that models of citizenship built exclusively on a liberal understanding work to create contradictions between pedagogical and political representational practices in the activity of ID based self-advocacy groups. The key then is to strike a balance between pedagogical facilitation and creating an authentic and respectful space for people with ID to voice, as well as crystalize their political positions.

Such a space is necessarily built on a communicative and dialogical approach to pedagogy (see Gomez et. al, 2006), since this is one of the few approaches that does not inscribe the pedagogical process with an a-priori asymmetry of knowledge and competences. This is the case since it entails establishing a climate of epistemological equality among actors (including academics, people living with ID, their allies, policy makers, etc.).

Another reason why the approach should be pedagogical is that it should be geared towards creating an appropriate mode of communication, when this appears necessary. Such a mode of communication could be based on using pictograms and recordings, as well as simple language whenever necessary. All the pedagogical intervention modalities should be designed with the help of self-advocates living with ID.

Recent years have brought forward noteworthy developments in including people with ID in national surveys from which they were previously excluded (see Malan, Emerson & Davies, 2014), as well as in local, national and European political decision making processes, as the story of the self-advocacy group *Ceva de Spus* shows. These initiatives should become mainstream, by politically involving a growing number of people that have been de facto depoliticized by subsequent layers of infantilization.

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References

- Ceva de Spus website <http://www.cevadespus.ro/despre-noi> accessed on 27.01.2019
- Committee on the Rights of Persons with Disabilities [CRPD] (2012) Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012), available https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en accessed on 27.01.2019
- Constituția României, available here http://www.cdep.ro/pls/dic/site.page?den=act2_1&par1=2#t2c2s0sba36 accessed on 27.01.2019
- Convention on the Rights of Persons with Disabilities [CRPD] (2006), available here <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> accessed on 27.01.2019
- Decretul 770/1966 available here <http://www.legex.ro/Decretul-770-1966-363.aspx> accessed on 27.01.2019
- European Agency for Fundamental Rights [FRA] (2010) The right to political participation of persons with mental health problems and persons with intellectual disabilities available at <https://fra.europa.eu/en/publication/2010/right-political-participation-persons-mental-health-problems-and-persons> accessed on 27.01.2019
- European Agency for Fundamental Rights [FRA] (2010) *The rights of people with mental health problems and intellectual disabilities to take part in politics* available at <https://fra.europa.eu/en/publication/2010/right-political-participation-persons-mental-health-problems-and-persons> accessed on 27.01.2019
- European Union Agency for Fundamental Rights [FRA] (2014) *Can persons deprived of legal capacity vote? Indicators on political participation of persons with disabilities*
- Gherguț, Alois; Frumos, Luciana & Raus, Gabriel (2016). *Educația specială: Ghid metodologic*. Iași: Polirom
- Gómez, J.; Latorre, A.; Sánchez, M.; Flecha, R. (2006) Metodología comunicativa crítica. Barcelona: El Roure, Chapter 2, English translation available here <https://pdfs.semanticscholar.org/c576/e979e2a688fc6978b1da9ce5dadf89f3d183.pdf> accessed on 27.01.2019
- Legea 3/1970, available here <https://lege5.ro/Gratuit/gu4tmobu/legea-nr-3-1970-privind-regimul-ocrotirii-unor-categorii-de-minori> accessed on 27.01.2019, the law was substantially changed by government decree in 1997.
- Malan, Sally; Emerson, Eric & Davies, Ian (2014) *Challenges in the first ever national survey of people with intellectual disabilities* in Tourangeau, Roger et al. *Hard-to-survey populations*, Cambridge: Cambridge University Press
- Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health & Illness*, 29(5), 767-786.
- Romanian Constitution, available here http://www.cdep.ro/pls/dic/site.page?den=act2_2&par1=2#t2c2s0sba36 accessed on 27.01.2019
- Roșan, A. (Ed.). (2015). *Psihopedagogie specială. Modele de evaluare și intervenție*. Iași: Polirom
- Roșan, A. & Bălan-Baconschi, C (2015) *Dizabilitatea intelectuală* in Roșan, A. (Ed.). (2015). *Psihopedagogie specială. Modele de evaluare și intervenție*. Iași: Polirom, pg. 99 -123

Verza, F. E. (2002). *Introducere în psihopedagogie specială și în asistență socială*. București: Editura Fundației "Humanitas".

Introduceți text aici