## Taboo, Hijack or Fatalism as Culturally Learned Qualities of Bonds by Families caring for Males and Females with Intellectual Disabilities at Homes: Secondary Data Analysis

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## Abstract

The article is a secondary qualitative data analysis report from cultural perspective on 3 generated in emic perspective categories called: qualities of bonds learned, supported and transmitted by Polish families having adults with intellectual disabilities and conditions that need home-based care for their entire lives. Performed secondary data analysis is grounded in the content of existing 3 Polish qualitative datasets from primary research undertaken in years 2005 to 2014.

Preliminary results of secondary analysis have indicated the existence of various culturally learned qualities of bonds in Polish families caring for adults (males and females) with intellectual disabilities as well as with multiple developmental disabilities. I have analyzed 3 main patterns of culturally learned qualities of family bonds as: taboo, hijack and fatalism.

**Keywords:** Cultural knowledge transmission, culturally based learning, lifelong learning, generational families, kinship, adulthood, females, males, intellectual disabilities.

## Introduction

Kinship, bonding, generational or procreative families are important points in the cycle and space of life of adult Poles with intellectual disabilities. They are also the center of many years of foreign and Polish research conducted in different paradigms and disciplines, over families with adult members with intellectual disabilities who need long-life home-based support and care.

In this paper we discuss and analyze 3 cultural patterns and qualities of family bonds and interpret or reinterpret selected problems that exist in generational families living in a common household with adult children having various intellectual disabilities. My next objective is also to initialize questions for further exploration of culturally meant family ties.

The text consists of structural parts illustrating in turn the anthropological view of the family, the phenomenon of family ties, the problem of bonds and intimacy, artifacts, routine activities and rituals. we present the overview of Polish concepts and research in Polish families caring for adults with intellectual disabilities and go to the results of learned and supported qualities of bonds. Then we analyze the 3 qualities and patterns of family bonds as preliminary secondary data analysis of primary data. Among described and analyzed cultural patterns are: taboo, hijack and fatalism.

## **Anthropological Focus on Family**

**Kinship**: By reviewing specialist literature in the area of kinship, we agree with the thesis that for anthropologists ranging from Malinowski<sup>1</sup>, Service<sup>2</sup>, Segalen<sup>3</sup> and Stanisz<sup>4</sup> kinship in any community from early to contemporary, is based on blood ties and marriages. For Service<sup>2</sup>, kinship is a concept evolving and changing over the years. de Good<sup>5</sup> pointed to the importance of kinship for his inventor, lawyer and anthropologist Lewis H. Morgan (1818-1881) who had once surveyed on the terminology of the concept of kinship. Morgan created the typology of kinship in different cultures. According to de Good<sup>5</sup>, the author identifies the relationship with the domain of culture.

Segalen<sup>3</sup>, a French ethnologist, believes that the word kinship (ancestry) can be found in dictionaries, but in every language, it loses its foundation and is not commonly used in everyday language but rather interchangeably with the word - family. The earlier ambiguities, in the semantic layer of the notion of kinship, were consistently carried forward, to modern times. The family identifies persons who are related to us, i.e. father, mother, sisters, brothers, uncles, aunts and cousins, through blood or marriage, while kinship is an institution that regulates the functioning of social life to a great extent<sup>3</sup>.

The author raises an interesting question about why kinship is important. She says, "In today's society, it seems that spouses are accidentally found in the office, dancing, or on vacation while the house or apartment still by means of press advertisements. In many societies, marriage, work depends on the place of the person in the organization of kinship and the entire organization of society regulates groups of kinship, whether in economy, politics or religion"<sup>3</sup>. For Segalen<sup>3</sup>, the essence of the category of kinship can be seen in the non-coincidences of ties and their order in the broader social structure.

Malinowski<sup>1</sup> emphasized that every human culture is built on the kinship system i.e. the type of personal ties and the kinship itself evolves and transforms in the course of life.

One of the important characteristics of kinship is, according to Malinowski<sup>1</sup> to regulate this bond with provisions in legal acts and treaties and traditions, almost unspecified.

What is the phenomenon of people in families? Malinowski<sup>1</sup> listed successively single qualities emphasizing that they are analogous regardless of the level of culture. He pointed out their universal character. The author contends that the everyday life of people involves "the intimacy of family life, the daily cycle of meals, home and work from home, night rest and waking up to a new day"<sup>1</sup>. The author expressed the view that there is an analogous pattern that identifies the phenomenon of closeness (intimacy) in the societies he was studying as well as in European culture.

**Closeness and Bonds**: What is the phenomenon of closeness in families? According to Malinowski<sup>1</sup>, attachment to one another, the sharing of life and the majority of his activity, the communication of self-help, companionship, companionship, distress and economic cooperation are related. The author felt that "the same forces unite our family and the same distance and barriers separate it from other families."<sup>1</sup>. By agreeing with the thinking of both Malinowski<sup>1</sup> and Segalen<sup>2</sup>, we think that bonds in a kinship are unique emotional and communication ties based on a daily co-existence in one's life.

The emotional dimension of family ties is also indicated by Carsten<sup>6</sup> who emphasized selected semantic qualities in the background of the bond. The author mentioned: the manifestation, the embodiment and the ritual-legal entanglement of bonds. Carsten<sup>6</sup> identifies kinship with the type of "embodied bonds that are obvious to almost every person, saturated with intensity and emotion."

Among other interesting concepts which indicate the context of the manifestation of family ties, we would like to point out two important artifacts - dining table - reviewed by Tadashi<sup>7</sup> and routine and family rituals explored by Wolin and Bennett<sup>8</sup>.

In discussing the concept of family ties in the context of artifacts, we would like to draw attention to the consideration of the family home as a family space and binders in interpersonal relations in the generational families of adults with intellectual disabilities as places of similar character as pointed out by Utracka<sup>9</sup>. "In anthropological interpretations, the symbolism of the home can thus explain the natural aspect of human existence, or biological (the bond of kinship within the family) which then determines the social order (union of families, dynasties)"<sup>9</sup>.

The author continues that "in the anthropological perspective, the house and its creation over the years are both a microcosm and a macrocosm. The analysis of archaic rituals shows that the house always created an indivisible whole with a human being and more precisely with the family"<sup>9</sup>.

The house is therefore immutable from the time of the Archaic; the place of creation and upholding family ties is the world and the microcosm, which can sometimes be seen looking at the lives of adults with moderate, severe and profound intellectual disabilities or multiple developmental and other disabilities for which the garden, sitting on a bench or walking along a lawn fence, sometimes referred to space of the property. The house becomes the world, what is behind the fence is only viewed under the care of relatives, sometimes supported by artifact called – wheelchair.

Artifacts: The second important artifact and bonding context also in families with people with disabilities is in my opinion the table at which the family eats meals and a place called dining room as well; sometimes the bed or bedroom where member with disability spend most of his/her daily time, garden etc.

Interesting relationships between family bonds and table and meals in Japan were reported by Tadashi<sup>7</sup>. The author has written a report on cultural studies and data analysis of the subject "Changes in family relations manifested at the table, from the perspective of" Theory of the Family Theater". Among the many quoted sources, the author recalled a novel written by Fumiko in 1979, "House without a Table". In the book, the author suggested that "the dining room table is a prop, around which the family eats together meals that can be understood as a symbol of the" family community "<sup>7</sup>.

Tadashi<sup>7</sup> pointed out that the transformation of the cultural role of the Japanese table has evolved over time. Changes related to the manners of behavior at the Japanese table and the food that was served. The author stated that changes in interpersonal relationships within the family were reflected at the dining table. The way they behave when family members gather around the table should be the best indicator of the nature and content of emotional relationships and family bonds. One of the interesting conclusions of the author was that in spite of the crucial role of the table as the place of family ties, the table in the dining room is constantly overlooked in conventional family studies.

completed descriptive research aimed at Tadashi<sup>7</sup> explaining, analyzing and describing the background of changes in some relationships and family ties that manifested itself in post-war Japan. In order to capture the essence of the changes, the author concentrated on those that took place in the dining room as a family space and above all at the Japanese table.<sup>7</sup> In the conclusion of interesting descriptive research, the author wrote metaphorically "in the search for 'householders at the table' (the direction of the evolution of the family in which it should go) we must create our own general scenarios. At the table the craft of family life must be worked out. We need to rethink a stage pro, known as a table, find it in every family and create original scenarios that match the character (family members). Parents (especially mother) are the creators of this family-building process".<sup>7</sup> In his conclusion, the author emphasized the

unique role of the table in creating family ties as well as the variety of ties that are created in different families. An important female creatively engaged in building family ties at the table in post-war Japan was mother in the opinion of the author.

**Routines and Rituals:** The third context in which family ties are manifested are family routines and rituals. Spagnola and Fiese<sup>10</sup> wrote about family routines and rituals and their impact on family development in the article titled: "Family Routines and Rituals. A Context for Development in the Lives of Young Children". The authors defined both routine activities and rituals as "specific, repetitive practices that involve two or more family members. They are diverse and can be differentiated in terms of communication, commitment and persistence "<sup>10</sup>.

Spagnola and Fiese<sup>10</sup> have identified after Wolin and Bennett<sup>8</sup> that routine and ritualistic activities, characterized by communication can be instrumental and involve timeconsuming or regular repetition, without special significance for participants. Family rituals include communication of symbolic meaning, setting the stage for solidifying knowledge about what it means to be a member of a group. The authors have stated that engaging time and continuity in ritual participation often exceeds "here and now" and may include repetitions from one generation to the next. Family rituals can include celebrations (such as festive endings), traditions - such as annual birthday parties) and interactive patterns such as the common, family meal<sup>8-10</sup>.

According to Spagnola and Fiese<sup>10</sup>, ways to understand the difference between routine and ritual activities may be to consider the effects that can cause disruption of these two permanent practices in the family. Ritual disturbances can threaten family cohesion<sup>10</sup>. In the conclusion of the subsection, the authors state that "both routine activities and procedures and rituals have a specific potential to serve and fulfill in the family an important role in maintaining the structure and emotional climate of daily family life"<sup>10</sup>.

Although rituals and routine activities are different from each other, they are quoted by the authors, interwoven into daily interactions. Spagnola and Fiese<sup>10</sup> have noted that dinner is not just a routine activity or a ritual but rather involves both. The meal itself allows to practice activities that may not need special attention such as food distribution, table cleaning and dishwashing. However, the authors point out that significant symbolic aspects such as common prayer, the transmission of commonly-told stories, or special dishes for certain days of the week such as the Sabbath dinner, can also be incorporated in the meals. In this way, the meal time reflects both the routine and the ritual. The practical end-ofmeal activities may be similar among families and families may practice similar rituals<sup>10</sup>.

According to the authors, rituals can be varied and specific in individual families, reflecting the identity of the family, family culture and common values. Set in the intricacies of family life overnight, routine activities and family rituals provide conditions for the development of children<sup>10</sup>.

In concluding the above considerations of the authors, in my opinion, both home artifacts such as the house, table and routine activities and rituals, create space and context for family ties in generational families, including families without members with intellectual disabilities and families with adult females and males with intellectual disability. The differences may concern not so much the quality of bonds "in the background of the table", but also the routine activities and rituals associated with the preparation, in special dishes (and kitchen equipment) - cups with beverages, so that members of the family with severe or profound intellectual disabilities can use it and participate at the table.

It can also be present as a routine activity in Polish families, regular doing the activities, work for in the members with disabilities as: preparation of sandwiches, breakfasts or dinners. In addition, regular insertion of meals for adults with intellectual disabilities is sometimes associated with the customs and rituals of Polish families. Constantly the issue of rituals at the family table requires further exploration and analysis in disability cultures.

## **Polish Families caring for Adults with Intellectual Disabilities**

Continuing the discussion on the bonding of the Polish families reported in social sciences, we would like to point out some of their several aspects of incompleteness in the background of the current research. One of the topics pointed out by Stanisz<sup>4</sup>, who noted a particular correction where it was believed that the Polish social sciences "for a long time did not seek new interpretations from which they could interpret family in an alternative way"<sup>4</sup>.

The second issue of incompleteness of Polish contemporary family research with members with disabilities was pointed out by Żyta<sup>11</sup>. The author rightly emphasized that the regularity of research on families with children with Down syndrome (i.e. with intellectual disability) focuses primarily on childhood and only in recent years have they taken into account the trend of family research in the context of different stages of family life.<sup>12</sup> As for the area of family research with people with intellectual disabilities, it is also difficult to disagree with Żyta<sup>11</sup> in the report on the study of narratives of family members and adults themselves with DS that "there is a lack of research covering the whole life of persons with DS"<sup>11</sup>.

The above comments of Stanisz<sup>4</sup> and Żyta<sup>11,12</sup> are interesting observations pointing to the gaps of contemporary Polish scientific discourse in the social sciences, manifesting on the one hand the unilateral nature of the research so far, the lack of new contexts and interpretative ideas and on the other hand, lack of processual research among families with adult

members with intellectual disabilities including life-cycle research, life-course, or life history.

However, we would like to make a remark at this point, pointing out below the most important Polish papers on the problems of families with members with intellectual disabilities. The works include generational and procreation families. Polish researchers have developed and developed theoretically or empirically, in various paradigms (positivist and constructivist), selected categories from the family life of people with disabilities, in general.

After preliminary analyzes, we distinguished the following categories, which are the research problems of research conducted in generational families. They are: a family with a child with intellectual disabilities and its multi-faceted functioning, siblings, maternity, paternity, partnership planning, procreation families for adults with intellectual disabilities or marriage. Taking a closer look at the problems of generational families, in theoretical or empirical contexts of research reports, the author's monographs or earlier works edited by psychologists seem to be crucial.<sup>13-23</sup>

Subsequent research by special educators dedicated to generational and procreative families with members with intellectual disabilities or their visions of adulthood, was carried out by the following researchers. We would like to say that the family and siblings were devoted by Żyta<sup>11,12,24</sup> in her research. Motherhood was explored by Szłapowska-Lizoń<sup>25</sup> and Lindyberg<sup>26</sup>. Relationships, marriage plans of adults with intellectual disabilities were investigated by Nowak-Lipińska<sup>27</sup>, Rzeźnicka<sup>28</sup>, Materny<sup>29</sup>, Zawiślak<sup>30</sup>, Górnicka<sup>31</sup>, Drozd<sup>32</sup>, Krause, Żyta Nosarzewska<sup>33</sup>, Krzemińska Lindyberg<sup>34</sup> and Kijak<sup>35-37</sup>. The problem of marriage and parenting of adults with intellectual disability was taken up by Grütz<sup>38</sup>. Family and paternity surveys were carried out by a sociologist Zakrzewska-Manterys<sup>39-41</sup> as well as by Nowak<sup>42</sup>.

In analyzing the rich subject and subject data, in the context of cultural analyzes, we tried to find and create a preliminary sketch of cultural patterns of family bonds in families with adult members with intellectual disabilities. During entire projects we analyzed reports from biographical, ethnographic and qualitative case studies from 2005-2014. Research reports including analysis were written by Lindyberg<sup>26-34</sup>, Piwowarska<sup>43</sup>, Kowalik<sup>44</sup>, Nowak<sup>42</sup>, Stanisz<sup>4</sup> and others.

## Secondary Qualitative Data Design

The analyzes were carried out in search of cultural subjects according to Spradley<sup>45</sup>, Borowska-Beszta<sup>46</sup> and qualities of bonds present in Polish families having own adult children with intellectual disabilities at family homes. We prepared analysis considering finally 3 datasets of qualitative data and 3 studies based on primary data published in the books by Żyta<sup>11,12</sup> and Lindyberg<sup>26,34</sup> and in the report written by Piwowarska<sup>43</sup>. Three datasets were derived from studies

conducted by the authors as biographical studies and case studies. Considering the framework of this article, I narrow down the analysis to indicate the three main cultural themes.

## Results

We present the generated 3 cultural themes as quality of bond and approach culturally learned, supported and transmitted by members of chosen Polish families with adults with intellectual disabilities. These cultural topics are a kind of cultural knowledge in generative families. These patterns should be considered in the specific context and cultural and social conditions of Poland, the post-communist country which was colonized by the USSR from 1945-1989. Therefore, family-based models of quality bonds and the approach to the situations in cases of long-term care in homes can also be anchored in a given cultural and political context of Poland, despite the collapse of communism in Poland was 28 years ago.

# Learned Supported and Transmitted Qualities of Bonds

**A. Taboo - silence about the future care obligations: "It seems to me that at home it is so accepted. No talking.":** The tabooed stuff can have many dimensions in my opinion. The word of taboo is ambiguous for cultural anthropologists. Wasilewski<sup>47</sup> defined taboo as a set of attitudes with very heterogeneous and intrinsically contradictory characteristics. According to the author, "imposed on a man without his thoughtful consent, irrational, unreadable, uses symbolic language, forgotten by a rational part of the mind"<sup>47</sup>.

On the other hand, taboo defined by Fershtman, Gneeza and Hofmann<sup>48</sup> is "unacceptable, or even with the thought of violence, strong social norms, the consequence of which is the social punishment. Taboo is a kind of social police discouraging some action. Taboo according to the authors, has different strengths and its intensity is variable over time"<sup>48</sup>.

Having in mind the analysis of research reports on intellectual disability studies and case studies from 2005-2014, we have generated several forms of tabooing cultural bonds in generational Polish families with adult members with disabilities. The first taboo area is excluded from open communication issue related to adult sibling care of disabled brother and sister after the death of parents. The taboo of this problem means an unwritten rule of silence. The breaking of silence could have unpredictable consequences for other members of the family. Why this is happening?

Żyta<sup>12</sup> has made an interesting qualitative analysis of interviews with 26 mothers, 10 fathers and 6 siblings of adolescents or adults with Down's syndrome. After reinterpreting the data from the family research and primary dataset published by Żyta<sup>12</sup> and content showing the perspective of mothers and siblings, we found the motifs of the taboo as the problem associated with silence between

mothers and siblings without disabilities about future care of disabled brother and sister after parents' death. We noticed lot of silent tensions and culturally learned and supported patterns concerning care duties. An interesting quality of bound rejected open communication speaking of future care and duties. The theme became tabooed and untouched silence as an internal agreement that constitutes the family law and rule and the quality of this taboo in particular family.

Żyta<sup>12</sup> writes about siblings: "children without disabilities - despite the fact that they often do not talk to their parents - feel that parents are expecting them to take responsibility for their disabled brother or sister in the future."

Below we share the tabooed content in the statements of siblings of brothers and sisters with intellectual disability concerned the future care after the death of parents.

- "It seems to me that at home we are so welcome, without talking, that I'm just going to take care of him. "Brother? I do not know. Maybe it came from the relationships we have in our family"<sup>12</sup>.
- "Mom never asked me about it. I cannot imagine that I could leave him without help"<sup>12</sup>
- "I have such a quiet arrangement with my brother that when our Mum passes away, Ania, will live with us, especially with this one brother who will earn better money and whose wife will accept Ania."<sup>12</sup>
- "Parents are sure worry about the future. We tried to make such conversations, but somehow they were mingling, on the principle - and there is still time "<sup>12</sup>
- "I do not know what the future of K will look like, I always expect M [the second daughter] will help because K loves her a lot ... But that's what I'm afraid of very much and have to honestly say"<sup>12</sup>.

We would like to mention also the second example of tabooed cultural bond in the family, we noticed after conducting my own research<sup>49</sup> where the characteristic taboo connection illustrated the lifestyle of Chauncey's 40-year-old blind male with mild intellectual disability, excluded totally by his parents from the Polish education system in 70s. Chauncey 44 years old presently cut off forever own entire and obligatory in Poland education on second grade of primary school. Taboo in family ties was strongly based on silence about his disability and total exclusion of blind child from education system. Chauncey did not attend any other school and was not a participant in the Polish education system, but as a 40-year-old was finally admitted to the occupational therapy and day care workshop.

**B. Hijack – hijacking of personal space real and symbolic "Can you not intrude on our affairs?":** The first association with the hijack type bond will probably be to search for a wider inclusion category. Some people will have in mind specialist literature about the symbiotic relationships of mothers and adults with disabilities. We can agree that this bond is a kind of difficult parental bond, described from the clinical perspective by among others Kościelska<sup>13</sup> identifying the maternal bond with a disabled child with difficult maternity.

What is the hijack bond, existing in family with adult member with disabilities in my opinion? Based on preliminary data analysis, we observed that this type of bonding involves the active hijack of the real or symbolic space of a young female or a male with intellectual disability by the other family members within a kinship relationship.

Case study research took several months of participant observation, ethnographic interviews of 59-year-old mother with adult son with intellectual disability in mild level associated with hearing loss and vision impairment. The study was conducted by Piwowarska<sup>43</sup> who stayed in a 4-person family consisting of parents and two adult children for several months and collected the following data.

Piwowarska<sup>43</sup> conducted a total of 12 ethnographic, thematic interviews (6 with a mother, 59 active in non-governmental organizations and 6 with an adult with Paul her son). The research was based on the prior consent of two study participants and coding of personal data. The researcher changed the name of the man, the participant and encoded the site, providing anonymity.

The author of the study wrote in notes and observations:

On the first visit, on February 2, 2013, I wanted to familiarize myself with the participants of the research. After the interview, I was leading a free conversation. Because Paul was expecting, the guest was my first informant. We were sitting opposite each other. We separated from the bench. His mother sat at the desk. Paul had long wondered about the answers, it was difficult to associate facts for him, he spoke very vaguely, it was a great hindrance for me.

When Paul pondered the answers, his mother began to whisper "hints" to him. I did not expect it but I asked her to speak loudly because neither I nor Paul heard her whispering well. So, Paul's mother became a participant in every interview with Paul. I did not mean it, I did not comment, I let it go free. On the same day (02<sup>nd</sup> Feb. 2013) I also witnessed a certain event which was the arrival of Paul's friend to their home.

Mom went to the door to greet him. During the removal of the shoes he had to answer a few questions asked by Paul's mother (how old he was, where he lived, how he knew that there was a place in the Occupational Therapy Workshop?). Then she asked me: what do I think of him? And is he not too old for a friend for Paul? I smiled and said that if they get along, it does not matter. She then admitted that she had to check who was coming to Paul and how it was a new person that had to "pilot" those contacts, usually when someone comes to him and hears them talk in the neighboring kitchen. Shortly after, I said goodbye and went out " $^{43}$ .

The author continued the descriptor as follows: "During another interview (20<sup>th</sup> Feb.2013), as usual, I started by explaining the topic. Paul's mother always read the questions prepared for Paul. When I told Paul what would be the subject of our conversation today, my mother began to read the questions aloud and give examples of answers. This interview looked a bit strange. Paul responded very scantily, not even thinking about the answers as in the previous conversation. He was still looking at his mother "<sup>43</sup>.

The researcher wrote also: "during subsequent conversations, Paul was less constrained. This is also visible in the content of my material. Interviews were without complications. Paul is a 20 years old male who feels like a nice and well-mannered man. He is a man with a mild intellectual disability, with a deep hearing deficit and a visual impairment and always dressed neatly. When I came to his house, there was music in the house".<sup>43</sup>

Analyzing the data mother hijacked Paul's space, what she exactly expressed during the course of the interview, constant verbal control about the questions and the responses that Paul (in his view) could have handled independently. The hijacked space also involved crossing the barrier of corporeality of adult male Paul by his mother during the interviews and thus controlling him even with other nonverbal signals as critically as he himself answered the questions of the researcher. An unusual example is the domination of Paul's intimate space - the washing of an adult male with intellectual disability in a mild level. Mom is still washing Paul, although he is a physically fit man. Mom is doing this because, in her opinion, the washing process lasts too long if Paul is doing this by himself.

As it turns out, the process of hijack of the symbolic and real space of Paul took years. Mom says "washing is very different. He will go into the water, the water has to the neck, but he sings in that water he will not wash. He just sings all the time. I have to go in, I show him, because he claims to wash himself. I see the head not washed, the ears not washed, the neck is not washed. He will lie in the tub and he will think that he is washed. Again, there is rebellion, he is an adult. But I say, "Paul you did not wash." I always say: "Fa -soap". It smells good! - I encourage him to do this. He will lie down and he sings. And I have to pilot it all the time. Because he claims to be an adult, but he is not. All you have to do is watch over him and watch him."<sup>43</sup>

The hijacked space, in my opinion, concerns Paul's mother's dominance - the course of the interview, his constant control, the questions and the responses that Paul, in his view, could

have handled independently. The appropriated space also involved crossing the barrier of corporeality, touching Paul and thus paying him as critically as he himself answered the questions of the researcher.

As I noticed mother hijacked and refused to give Paul the freedom not only to occupy his symbolic space (in the sphere of communication and language) but also real situations and world. I would like to emphasize clearly that the relationship in question is not a non-lucid one, on the contrary. Piwowarska<sup>43</sup> writes that love of mother and care can be observed easily. Mother says: "I do not let Paul go far, because he will not get back. But I'm checking it here around the house. On the playground I see him and he adjusts. I trust him that he is there. I will often check him what he really does. Often the will go to the park after him here (district name). Well, how often do I check that? I do not have to risk whether he goes home or not, I do have to risk that he must be somehow independent and I have to trust him too. Yes? I just have to trust him."<sup>43</sup>

Other data indicate something opposite because mother continues: "I often follow him, whether he will hit or not, because Paul has a memory loss. But I say I have to risk letting him go alone. He has a mobile phone, he can handle it, I often guide him through the cell. Where is he going to get off or go back like he's gone and somehow cope? There are still jobs to do and these device increases safety for our disabled children".<sup>43</sup>

Mom also has a great deal of control over Paul's friendships. When Paul met the girl, mom immediately took control of her acquaintance. During one of the telephone conversations with Paul, his girlfriend, irritated by Paul's behavior, girlfriend asked him to talk to his mother. In the mother report appeared the following conversation: "Paul give me your mom". Mother and so ugly she said: - can you not intrude on our affairs?".<sup>43</sup>

Piwowarska<sup>43</sup> wrote, "in the life of Paul the mother plays the main role. Continuous steering and piloting were conducive to his physical and intellectual passivity. Paul became accustomed to this and this caused his mother to fill all the fields of his life. Paul, through his disability, had a difficult relationship with his peers. They also did not keep up with the constant mastery of his mate both with his friends and colleagues. If some friend or colleague seemed to be inadequate, mother could finish such a relationship. When interviewing, I often felt that mother was upset when Paul was talking about girls and intimate matters. She applauded him when he answered her world view and was annoved when he said something from himself, which she did not support. During pauses, when Paul was pondering the answers, his mother began to tell him and even answer for him.

Paul's nature and autonomy are "piloted" by his mother. Mother thinks that Paul is still not completely independent and needs care from her side. Responding to my research questions, I conclude that Paul's mother did not create the situation that Paul could decide for himself and make his own decisions. Paul's mother has always been with him in very close relationships. Paul could count on her at any time. Surrounded by tremendous support he has survived worse moments of his life. His mother stresses that she never gives up<sup>43</sup>.

Piwowarska<sup>43</sup> noted that the relationship between the mother and the adult Paul is characterized by crossing the border of privacy connected with washing, physically fit, adult male with mild intellectual disability and sensory dysfunctions. Mother is usually answering for him, controlling conversations with peers, eavesdropping and selecting friends of Paul. According to the author of the study, Paul is a humble person who when rebels is punished by a lonely stay in his room. "The mother's concentration on Paul turned into something unnatural, into a "piloted" relationship. This relationship is conducive to intellectual passivity and lack of independence of Paul<sup>43</sup>.

When analyzing the primary field notes and other data as well as interpretations of Piwowarska<sup>43</sup>, I saw in this family a family bond clearly indicating form of hijack. Paul's mother, like a hijacker took his life space totally. Wherever Paul goes in the real world, there is a mom. I would like to point out that in the indicated hijack bond real space has been hijacked in its various dimensions (from intimate to public) and the symbolic space either.

Paul does not have the capacity to be an autonomous person, he is able to cope with the situation of total hijack, even while interviewing. He adjusted to this kind of total hijack rarely rebelling when it is about intimate relationships with girls. Mother as the hijacker is however much stronger to give Paul more psychological space for life.

**C.** Fatalism – fatal external and inevitable influences: "We are sitting here like bewitched. Grandma sits in an armchair and speaks the same things over and over": Following this type of bond, I made analysis of two interesting biographical studies conducted by Lindyberg<sup>34</sup> and published in two chapters of the book, together with Krzemińska<sup>34</sup> title. "Around Adulthood with Intellectual Disability". After analysis I generated an interesting pattern of culturally grounded bonds in family, manifesting itself in the tacit knowledge as fatalism.

The first of these texts illustrates an in-depth analysis of the experiencing world of a male with mild intellectual disability and the other text showing the family's prospects of taming the future by parents of adult children with intellectual disabilities are also saturated in my opinion with the phenomenon of fatalism. According to Kopaliński's<sup>50</sup> dictionary, fate has Latin origin means etymologically - "what is said; pre-destination, what is done by the Gods, fate, destiny, necessity, fatality, bad luck, or misfortune"<sup>50</sup>.

The first of the analyzed texts of Lindyberg<sup>34</sup> title, "The biographical change of a person with intellectual disability as a chance for normal adulthood" - illustrates the fatalistic, dramatic and entangled life of an adult Simon (with mild intellectual disability and psychiatric disorders) who at the age of 5, witnessed suicide of his father. Simon lives with his mother, a female who, according to the author of the study, is behaving unconventionally during conversations - switching off at times.

Kristin, Simon's mother manifested active aggression towards his son. A witness of the dramatic situation was the researcher during data collection. Lindyberg<sup>34</sup> writes "During one of these conversations, Kristin was upset at her son, then took a lying binder from the table and began to beat Simon on his head with all her might. This tall man only covered his face and surrendered to his mother"<sup>34</sup>.

Simon's reaction is puzzling and humble, not only for the author of the study. Such passivity and surrender of Simon's to fatalistic external power and motherhood, most probably not the first reaction. He remained passive. Further interpretations and verbatim data came from another author's text in which Lindyberg<sup>34</sup> cited data also from her own biographical studies inspired by the tradition of symbolic interaction and realized among 7 parents of adolescents with intellectual disabilities.

The author analyzes the characteristics of adolescents' disability in the context of the process of taming the future of their children by parents. The text has an interesting structure in which the author, in addition to raw research data (verbatim), generated titles in the structure of own text which I might call broader inclusion categories that led me to construct the broader cultural bond category I named fatalistic.

Among the categories that illustrate parents' views on the adulthood issues of own adolescents with intellectual disabilities, Lindyberg<sup>34</sup> pointed out:

- "an anxiety-creating situation",
- "a situation that has not been chosen by themselves",
- "a situation that needs to be solved alone",
- "a situation marked by chaos"
- "the situation with which to fight",
- "the situation in which it is not known what a role to play".

These broader inclusive categories contain examples of verbatim data that has been collected by the author. The broader general pattern of qualities of cultural bonds, as outlined in the background of the family characterization of the situation (disability of adult children), is saturated in my opinion with fatalism manifested in the language of parents.

Similar fatalism, as we can indicate in the case study and field task by Kowalik<sup>44</sup> who interviewed the grandmother of

23-year-old Kacper's with cerebral palsy and severe intellectual disability. Kowalik<sup>44</sup> as the data collector in the field heard the following interpretation of the current situation and bond spoken by the grandmother. Grandmother with warm personality, who was the only caretaker of an adult male abandoned by his mother (her daughter) spoke about everyday life and ties with Kacper. She said, "We are sitting here like bewitched. Grandma sits in an armchair and talks the same things over and over "<sup>44</sup>.

Also, in the second case, is present the phenomena of fatalism and the external fatalist force which underlined the grandmother's bond with the grown-up grandson. Grandmother, a 70-year-old female is a warm and affectionate woman, reconciled in a non-claimant way, that her daughter left Kacper many years ago, founded a second family and Kacper does not visit. Kacper misses mother. Mom is present in his simple questions about her "and mom?" - what does mean - when will she come?

## Conclusion

In conclusion, I would like to mention that in addition to the above analyzed categories and culturally learned qualities (and not necessarily optimal qualities) of bonds as taboo, hijack and fatalism in Polish generational families with adults with intellectual disabilities - family still remain a solid background and a key place for living for many members with intellectual disabilities.<sup>49</sup> There is always the question about the improvement of family bonds related to public and cultural education that can involve concepts of independent living and especially much concentrated social work and efforts on home-based support for Poles with disabilities and their families.

Although in the text I have pointed out only the selected bonds saturated with taboo, hijack and fatalism, there is more cultural research needed to discover the dimensions of bonds as well. It should be clearly noted that generated by me does not exhaust the problem, since each of the quality of ties in the family may have different dimensions and content in taboos, hijack and fatalities.

Except that there are also possible other qualities of learned culturally bonds with completely different content reservoirs, furthermore there can be much more examples for saturation of illustrated in the article bonds as well.

Moreover, there is still further qualitative research to answer why the taboos in families with adults with intellectual disabilities may concern care after parents' death? Why mother of an adult with intellectual disability can hijack the personal space? Why adulthood of children with intellectual disabilities some parents see as fatalism in Poland?

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