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Special Feature Article

Tojisha-Kenkyu and Co-production of Research

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Abstract

In order to promote research on minorities that reflects the perspectives and values of minority members, co-production of research with the participation of the minorities is important. However, there are many issues to be addressed in its implementation. In order to collaborate on an equal footing with the expert community, which has been sharing and updating its knowledge synthetically and diachronically, it is necessary to have a counterpart community of minorities who also share and update their own knowledge. However, in the same way that the expert community is divided vertically by field, the minority community also tend to be divided vertically by similarities in hardships and needs. In addition, a community of people who are united by similarity will have a center-periphery structure, and marginalized members may be oppressed. Historically, tojisha-kenkyu was born as a way to give expression to the experiences of the marginalized members of the community, but if the silo structure of the community is preserved, it can become a technique that forces the marginalized members to over-adapt. In order to realize co-production, both the expert community and the minority community must be able to honestly express what they know in a safe place, acknowledge the limitations of their own knowledge and the existence of members and experiences that are marginalized by it. We must have a humble attitude toward the knowledge of other research communities, and make organizational changes to continue

to try to increase our objectivity by bringing in a variety of perspectives from outside the periphery.

Keywords: tojisha-kenkyu, co-production, marginalisation, humble leadership, psychological safety

Introduction

Expert knowledge has marked potential to enrich the lives of minorities. At the same time, there are instances when the goals of experts and desires of minorities diverge. For example, in the field of physical disabilities, until the 1970s, experts aimed to make the bodies of the disabled closer to those of the able-bodied, but the disabled people themselves developed the “disability movement” and desired to make the social environment, including buildings, tools, and systems, more accessible.⁹⁾ In the field of autism spectrum disorder (ASD), until the 1990s, support and treatment that conformed to the communication styles of the majority flourished, but those with ASD developed the “neurodiversity movement” and desired a communication style (autistic sociality) that was comfortable for them.⁸⁾ Furthermore, in the field of addiction, addicts have created “self-help groups” and found that sharing stories of their own habits and traumas that lie behind their use can help promote recovery, in

contrast to the approach of professionals who simply aim to get people to stop using drugs and alcohol.¹⁵⁾

In this way, the activities of experts leading to the creation of knowledge about or for minorities may sometimes go in a direction that differs from what the minority parties themselves are seeking. Therefore, there is a growing awareness of the need to promote research based on the perspectives of the parties involved and with their participation, and this awareness is being shared around the world along with the key phrase “co-production of research.” Co-production of research is an approach to promoting science and technology together with experts, in which citizens and stakeholders who are involved in the research lead all stages of it, including the allocation of research funds, formulation of hypotheses, experiments, analysis, and interpretation and publication of the results. It is becoming an important topic internationally, with a special feature on the topic being published in the journal *Nature* in October 2018.

Although there are increasingly fewer people who doubt the significance of co-production of research, there is still ongoing debate about how to achieve it. For example, a study analyzing the minutes of research projects that advocated co-production reported that the involvement of stakeholders was limited to formal and symbolic levels.¹¹⁾ Furthermore, there are also suggestions that being part of a research institution that is customized for the majority gradually assimilates minorities into the majority's values and cognitive framework, making it difficult to maintain minority perspectives.²⁷⁾

In order to deal with these limitations, it is important to have a minority community that shares and updates the values, perceptions, and practices unique to minorities both synchronically and diachronically, rather than having minorities working individually while being surrounded by the majority. It is essential that the minority community and expert community, rather than the minority as individuals and expert community as a group, collaborate in co-production.

An example of a minority community that shares and updates the values, perceptions, and practices unique to minorities both synchronically and diachronically is the grassroots research community known as "tojisha-kenkyu," which was established in

Japan in 2001. Tojisha-kenkyu is an approach in which "people with various difficulties do not simply leave the interpretation and handling of their own difficulties to experts, but instead re-evaluate them as research subjects that they themselves should take on, and together with their peers who have similar difficulties, they verbalize their experiences and explore interpretations and methods of handling their difficulties."

Since 2012, the author has been working on co-production, mainly with people with ASD, with funding from a Grant-in-Aid for Scientific Research on Innovative Areas and JST CREST since 2016. In April 2015, the Tojisha-kenkyu department was established at the Research Center for Advanced Science and Technology at the University of Tokyo, and in October 2018, a system for employing user researchers was introduced throughout the University of Tokyo in order to promote the participation of people concerned in all research involving human subjects. Furthermore, the author has also been involved in the methodological development and institutionalization of tojisha-kenkyu and co-production, including the history, philosophy, principles, related fields, case studies, and ²⁰⁾ points to note in co-production with specialized knowledge,²¹⁾ and specific methods of tojisha-kenkyu.²³⁾

In this paper, we will introduce the authors' approaches to *tojisha-kenkyu* and co-production, and consider the issues involved.

I. Marginalized “Tojisha” in Minority Communities

As mentioned earlier, in order to achieve equal research co-production, it is important to have a minority community that shares and updates the values, perceptions, and practices unique to minorities both synchronically and diachronically. However, as with any community, if we look inside a minority community, even if they share commonalities, there are diverse members who cannot be reduced to the same category. For example, if we look at the self-help groups for addicts and disability movement, which had a significant impact on the birth of *tojisha-kenkyu*, in terms of “openness” to the outside world, self-help groups for addicts have a rule that what is said within the group is not to be discussed outside the group, and this ensures a place where people can honestly and safely disclose information that involves risks, such as talking about their painful pasts.⁶⁾ In addition, the management policy clearly states that members must not express their opinions on political disputes outside the group. In contrast, the disability movement has aimed to bring about

social change by compiling the diverse content shared by each member as “our opinions” (where the uniqueness of each individual member tends to be disregarded) and making it available to the public. These characteristics of each group cause a division between members who fit in and those who do not, and they become marginalized.

In the disability movement, it was members with less visible disabilities who were marginalized. The needs of the core members were clear, as it tended to be an unspoken assumption that they had minority bodies, both by themselves and others, so all that was left to do was to advocate for social change. On the other hand, people with diagnoses such as developmental or mental disorders often have difficulty understanding the line between whether difficulties they are experiencing are due to their own lack of effort or an obstacle that they cannot remove. Their difficulties are hard for others to see, and difficulties that are hard for others to see are also hard for the people themselves to see. In the face of these problems, they become consumed with feelings of self-blame, wondering if their inability to act appropriately is due to a lack of effort or weak will. Many such people would not know what to advocate even if they were told to “make social change.” For these people, it may have been necessary to

start by discussing their unique experiences before they could be grouped together as “us,” and then to explore their knowledge of their own bodies.³⁾

Marginalized people also existed in self-help groups for addicts. The 12-step recovery program, used in many self-help groups for addicts, was developed by relatively well-off white men from the middle class or above. They had a place in society to which they could return once they had resolved their addiction problem. Programs that are targeted at such people may not be well-suited to those who lack social resources, such as those who are routinely subjected to violence at home, suffer from social discrimination or exclusion, or have multiple disabilities. For them, even if self-help groups are the only safe place, once they step outside, they are immediately confronted with a world of discrimination, violence, and poverty, and find that the only resources available to them to survive these difficulties are substances of dependence. These people include female, LGBT, and ethnic minority addicts. Unless the society that discriminates against them changes, they will not be able to thrive. They longed for the opportunity to be more open to the society outside of their group.¹³⁾

II. Birth of Tojisha-Kenkyu

Thus, for those marginalized by both the self-help groups for addicts and disability movement, which are both minority communities, a new kind of practice was needed that would allow them to explore their uniqueness in terms of both their bodies (derived from the disability movement) and their stories (derived from the self-help groups for addicts), and to connect this to social change by making it public (derived from the disability movement) without summarizing it as “our opinions” (derived from the self-help groups for addicts). This is how the concept of “tojisha-kenkyu” was born in Japan.

According to Ayaya,⁶⁾ in the 1970s, Ikuyoshi Mukaiyachi, a social worker who was assigned to the Urakawa Red Cross Hospital in Urakawa-cho, Hokkaido, had been exposed to the principles and practices of the movements of patients with intractable diseases and people with disabilities during his time as a student, and he had a desire to bring this to the field of mental disorders. At the same time, Toshiaki Kawamura, a psychiatrist from Asahikawa Medical University who was actively practicing addiction medicine, was fascinated by the stories of AA members he met when he was a resident, and wanted to apply this to all mental disorders. The encounter between Mukaiyachi and Kawamura,

two people who had a significant influence on the birth of *tojisha-kenkyu*, was also an encounter between the disability movement and self-help groups for addicts, in the field of mental disorders centered on schizophrenia.⁶⁾

What helped to integrate these two seemingly contradictory groups was the framework of “*kenkyu* (research).” By inviting *tojisha* who are facing difficulties to “research”, *tojisha* who responded to difficult situations with self-blame or the blaming of others become absolved and guaranteed a position as a safe observer, and conditions necessary for being able to think about difficulties in a more value-neutral way are secured. At the same time, as a kind of responsibility, there is also a demand for “knowledge of ignorance,” an awareness that one does not yet know enough, and “honesty” in trying to accurately describe one's experiences. These attitudes have been passed on to *tojisha-kenkyu*, mainly in the form of inheriting the traditions of self-help groups for addicts. In the disability rights movement, there is a tendency to prioritize attitudes such as “blaming experts and society for their shortcomings,” “knowing better than anyone else,” and “delivering effective messages strategically,” and it is not uncommon for people to stray from the knowledge of ignorance and honesty.

When it comes to research, there is a need for “openness” that strengthens objectivity by incorporating various perspectives through sharing and dialogue with those outside the group. By emphasizing openness, which was carefully avoided in self-help groups for addicts, *tojisha-kenkyu* inherits the element of social change from the disability movement.

Of course, in the case of *tojisha-kenkyu*, it is important to note that the political nature of the disability movement and safety of the self-help groups for addicts have been undermined, and since there is no replacement for the two existing practices, it is important to view *tojisha-kenkyu* as a third practice that coexists with them.*

Furthermore, using the term “*tojisha*,” it is also important to emphasize that the research subject is not a categorized disability attribute, but rather one's uniqueness. The theoretical framework and methodology of *tojisha-kenkyu* are detailed in the author's papers¹⁶⁻¹⁹⁾ and books.^{20) 22-24)} The main points are as follows:

Tojisha-kenkyu is an approach to studying oneself. However, what exactly are they studying about themselves? In the course of conducting historical research on Bethel House in Uraga and DARC Women's House, which have been practicing *tojisha-kenkyu* for

many years, participant observation of practical situations, and specific reviews of *tojisha-kenkyu*, we have come to think that the “self,” which is the subject of *tojisha-kenkyu*, can be divided into two broad categories:

The first is the “sense of invariant self,” which is a sense of oneself that remains unchanged over time and has a certain degree of regularity, including one's way of feeling, thinking, and behaving, as well as one's habits and patterns. This is an aspect that reveals the uniqueness of one's own body, and is extracted from the patterns that emerge when specific past episodes are listed, such as: “it was like this at the time” and “it was also like this at that time.” In addition, they constantly try to distinguish between the parts of the pattern that can be changed and those that cannot be changed through experiments in everyday life, and propose changes in the surrounding environment based on the parts that cannot be changed (invariant terms). The second is the “autobiographical self,” which is continuously changing over time but is still a continuous self as a single person. This is a historical aspect that explores the meaning of each individual episode by considering each episode as a single event, piecing together a personal history, and then locating each episode within the overall context.

III. Example of *Tojisha-Kenkyu*

The *tojisha-kenkyu* conducted by Ayaya, who herself had been diagnosed with ASD, is valuable in that it has led to a reconsideration of the concept of ASD itself through the pursuit of one's own uniqueness. Currently, ASD is defined by “difficulties in communication with others.” However, Ayaya has argued that the term “others” here refers to the human environment surrounding the *tojisha*, and that “difficulties in communicating with others” is a mismatch that occurs between the *tojisha* and their environment, and is not a characteristic that can be attributed to the individual as a diagnostic name. In other words, the criticism is that the idea of a “social model” that distinguishes between impairment, which is a characteristic that can be attributed to the individual and is the mainstream understanding of disability today, and disability, which is a mismatch between the environment and individual, has not been thoroughly implemented in ASD research.

Since 2008, Ayaya and the author have been examining Ayaya's *tojisha-kenkyu*³⁾ while comparing it with other *tojishas*' memoirs and previous research, in order to construct an ASD theory that incorporates the perspectives of the social model and *tojisha*.

Firstly, in order to verify the hypotheses about impairment derived from *tojisha-kenkyu*, we have conducted co-production and reported on various areas, such as: body image instability²⁾; a narrow personal space¹⁾; a marked autonomic nervous system response to tactile stimulation¹⁰⁾; being sensitive to prediction errors in feed-back and having weak feed-forward control based on internal models in voice control,²⁶⁾ and having a tendency to scan patterns of eye movement in facial recognition in a random manner.¹⁴⁾ This is an understanding of ASD based on the social model, which states that individuals with physical characteristics that differ from the majority are prevented from accessing a communication environment customized for the majority. Secondly, in order to clarify the conditions of a communication environment that is less likely to result in disability, we have examined the conditions that promote information acquisition and self-expression for patients with ASD in dimensions of communication styles, such as information presentation styles,⁴⁾ rules for taking turns in a conversation,²⁸⁾ and SNS design,¹²⁾ based on the knowledge of impairments mentioned above and findings regarding the design of communication that is easy for people with ASD to participate in that have emerged ad hoc

through the practice of *tojisha-kenkyu* by *tojisha* with ASD.

Thirdly, even if the environment of the ‘here and now’ becomes one that matches one's own body, memories of past mismatches can be traumatic, so we have been working to integrate one's own history through the sharing of stories.⁵⁾

Fourthly, it was confirmed that these series of *tojisha-kenkyu* were influenced by two preceding *tojisha* activities that had influenced the birth of *tojisha-kenkyu*, in the form of the social model derived from the disability movement and re-narration of traumatic memories derived from addiction self-help groups, and that they were being updated in response to these influences.⁷⁾

IV. Remaining Issues

The concepts of “safety”, “knowledge of ignorance,” and “honesty”, which guarantee the position of the observer/reporter who has been absolved of blame, and “openness,” which strengthens objectivity by incorporating various perspectives, are not only required for *tojisha-kenkyu*. Co-creation would not be possible without the existing expert communities, which are the other counterpart to co-creation, continuing to express what they know honestly in a safe environment, examining the limits of their own expertise, maintaining a

humble attitude towards the knowledge of research communities outside of their own, and incorporating various perspectives from the outside to improve objectivity.

At the same time, the *tojisha-kenkyu* community also needs to recognize the tendency to fall into a vertical structure that is segmented by the similarity of difficulties, in the same way as traditional expert knowledge. There is even a risk that a core-periphery structure is created within the fragmented *tojisha-kenkyu* community once again, and *tojisha-kenkyu* will be abused as a way of forcing self-reflection and excessive adaptation on peripheral members. In light of these issues, it is necessary to remember that the roots of *tojisha-kenkyu* lie on the periphery. It is only on this periphery that *tojisha-kenkyu* can be established to renew existing *tojisha* knowledge. In addition, members on the periphery often find themselves at the intersection of multiple difficulties. They are also members who have difficulties that can only be understood and dealt with by overcoming the vertical structure and connecting the *tojisha* communities.

In this way, co-production requires organizational change that puts the periphery at the forefront of both the existing expert and *tojisha* communities. Recent organizational research findings have pointed to the importance of

maintaining a skeptical eye on the shared stories of organizations, particularly organizations responsible for critical infrastructure where maintaining a high level of reliability is essential, along with concepts such as mindfulness and sense-making.²⁵⁾ Furthermore, even in more general organizations, it has been reported that: (i) “humility”, which is characterized by three traits: “exploring accurate self-understanding through engagement with others,” “acknowledging the abilities and contributions of others,” and “continuing to try to learn from others about what you don’t know,” promotes the wellbeing, engagement, and creativity of members; (ii) the effects of the promotion of creativity are mediated by the “psychological safety” of the team, which is characterized by “being able to safely disclose weaknesses, limitations, and difficulties and seek help” and “being able to take on challenges without being overly punished for failure”; (iii) the mediating effect is modified by the “degree to which members share knowledge” with each other.²⁹⁾ By creating a space where people can disclose their weaknesses, each member can recognize the contributions of others. *Tojisha-kenkyu*, which seeks to understand oneself accurately through interactions with others, has the potential to bring about

such a cultural environment in various organizations, not just for minorities.

The authors are currently receiving funding from the Ministry of Education, Culture, Sports, Science and Technology's Grant-in-Aid for Transformative Research Areas (A), and are conducting preliminary research to create a protocol led by *tojisha* to verify the impact of introducing *tojisha-kenkyu* into universities, research laboratories, and minority communities as organizations on three variables: "humble leadership," "psychological safety," and "knowledge sharing." This is an important topic not only for co-production, but also for universities and research institutions where there is a problem with the poor well-being and resulting poor creativity of graduate students and young researchers, such as at the first International Conference on the Mental Health & Wellbeing of Postgraduate Researchers to be held in the UK in 2019.

Conclusion

In *tojisha-kenkyu*, the term "*tojisha*" does not solely refer to minorities who have been assigned categorized attributes. All people who face various difficulties with their finite bodies and walk their own unique histories are *tojisha*. Through *tojisha-kenkyu*, I hope that both minority and expert communities will transform their

cultures in order to become more aware of the people and experiences that have been marginalized, and that a platform for co-production will be opened up, with humility based on the knowledge of ignorance.

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Note

* Ayaya, who is researching the history and methods of tojisha-kenkyu, reports on how the tojisha at Bethel House in Uraga use three different spaces -

Bethel's own SST, which was influenced by the disability movement; Schizophrenia Anonymous (SA), which was influenced by AA; and tojisha-kenkyu, based on their respective strengths and weaknesses.