

The evidence dissemination in collaborative environment: an international study and the practice of the dissemination process on the super-ageing of Down syndrome

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Abstract

In this research the author has shown that the life expectancy of people with Down syndrome has been increasing in Japan. Considering how this evidence should be utilized, the author has studied the experience of the UK, where people with disabilities and experts are working together to create a comprehensive international policy. As a result, the author has found that, to implement better measures for people with disabilities, we must approach the issue from both medical and welfare perspectives rather than a one-sided perspective and share the evidence with stakeholders who play important roles for policy-making. Furthermore, the author held a round-table discussion in Japan where she shared the evidence on the aging problems of people with Down syndrome and discussed the elderly Down syndrome together with medical and welfare experts. During the discussion the author also provided a place where participants with common concerns could talk to each other. As a result, most participants realized that the future of aging people with Down syndrome was not been planned or addressed, even though they seemed to understand it as a sensation. The round-table discussion generated innovative outcomes that could lead to future actions toward the social participation of aging people with Down syndrome.

*This study is conducted as a part of the Project “The evidence dissemination in collaborative environment: an international study and the practice of the dissemination process on the super-ageing of Down syndrome” undertaken at Special Research Project II and III in Graduate School of Advanced Integrated Studies in Human Survivability, Kyoto University.

エビデンスの伝達プロセスの検討と実践
—英国における国際調査及びダウン症の高齢化を事例とする保護者・当事者と専門家の対話の場作りを通じて—*

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要 旨

筆者は現在までに高齢化による影響が顕著であるダウン症者を対象とし、実際にダウン症者が長寿化していることをエビデンスとして示した。このエビデンスをどのように生かすべきか考慮し、本研究においてはまず、障害者当事者と専門家が連携しながら国際的な障害者施策の潮流を作ってきた英国において、障害者福祉の課題の抽出を行った。その結果、より良い障害者施策を実装していくには、一面的な視点からではなく、医療・福祉双方の視点からアプローチし、多様なステークホルダーをまきこみながらエビデンスに基づいてアウトリーチしていく場を作っていくことが重要であることがわかった。これを踏まえ、日本でもダウン症者の高齢化について筆者が明らかにしてきたエビデンスを伝え、医療と福祉の専門家を呼び、共通の心配をかけている方同士が語り合えるような場を設けた。その結果、多くの方々は感覚としてわかったつもりでも、高齢化するダウン症者の将来について実際に計画を立てたり、対応を講じるには至っていない状況にあったことが示唆された。

*本稿は、京都大学大学院総合生存学館における特殊研究 II, III の成果の一部である。