

Aims of the project

Around 0.6 percent of the German population live with a so-called intellectual dis_ability. The lower levels of health literacy they may experience have various implications, including the risk that they will not receive appropriate treatment for illnesses or engage with health promotion and disease prevention activities. This project is our attempt to help improve the situation of people with intellectual dis_abilities in their use of healthcare and health promotion services.

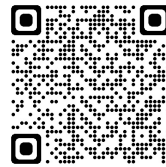
The project involves Advanced Nursing Practitioners (ANPs) – working alongside people with intellectual dis_abilities to draw up individualized health promotion and disease prevention plans for them on the basis of their specific needs and requirements. Over a period of 12 months, we support the study participants in implementing these plans and monitor changes in health status.

One aim of this new form of healthcare support is to identify the needs and requirements of people with intellectual dis_abilities with regard to healthcare and health promotion. The knowledge and experience of participants and the ANPs will be key to helping us create a health-promoting world for people with intellectual dis_abilities. We wish to reflect the diversity that characterizes the lifeworlds of people with intellectual dis_abilities by involving them as coresearchers in our project, empowering them to communicate their views, ideas and needs. Our structural objective is to prompt the implementation of this model of care as standard, incorporating its inclusion in statutory health insurance coverage in Germany.

Who we are

The members of our project team work at Hamburg University of Applied Sciences (HAW Hamburg), the social service provider Evangelische Stiftung Alsterdorf (ESA), Hochschule Bielefeld – University of Applied Sciences and Arts (HSBI), the Deutsches Krankenhausinstitut (DKI), and the statutory health insurers AOK Rheinland/Hamburg (AOK) and Mobil Krankenkasse.

The project is funded by the Innovation Fund of the Joint Federal Committee (G-BA).



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A collaborative approach to health promotion and disease prevention for adults with intellectual dis_abilities

Collaborating on this project



What we want to find out

Our research seeks to identify answers to questions as follows:

How can we help promote the health of people with intellectual dis_abilities?

What are the health promotion needs and requirements of people with intellectual dis_abilities?

How can we support physical and mental resilience and health literacy among this group and empower them to make their own decisions around their health?

Do people with intellectual dis_abilities enjoy greater health-related quality of life if they are engaged with health promotion services?

What are participants' perceptions of the ANPs' work with them on health promotion and disease prevention issues?

Can we identify obstacles and barriers to engagement with healthcare among this population, and what action can we take to dismantle these?

Our research process

The intervention

Our project centers on the drawing up of health promotion and disease prevention plans in a joint endeavor by people with intellectual dis_abilities, who are the plans' end users, and ANPs. The plans seek to promote health in the areas of mobility, nutrition, stress management and addictive behaviors. ANPs provide our participants with support on their journey to greater self-efficacy and improved health. We explore the impact of this close support from various perspectives.

Part of this entails dividing the participants into intervention and control groups. As it would be unethical to deny one group the support associated with the intervention, both groups receive the intervention, with one receiving it first and the other (the control group) at a later date.

The evaluation

An evaluation of the intervention's effectiveness is currently in progress, considering various aspects of its impact as follows:

- A) changes in the participants' health status, quality of life and resilience within 12 months (evaluated via a randomized controlled trial)
- B) how the study participants and the professional actors involved in the intervention evaluate it and how they have made use of it for themselves; this incorporates a standardized cross-sectional survey of participants, qualitative interviews with study participants and professional actors
- C) a document analysis to ascertain which types of action the participants and professionals planned and implemented during the intervention
- D) an analysis of cost-effectiveness, comparing the intervention's cost to its health-related benefits to the participants
- E) inclusive research for identifying the individual knowledge, experience and strategies that people with intellectual dis_abilities draw on for health promotion purposes



People with intellectual dis_abilities: coresearchers

We have established a working group consisting of 4-6 coresearchers from the study's target group and a researcher from HSBI. The members of the working group have the remit of providing their input to the intervention process and conducting interviews with study participants (see E).



Dissemination

We will publish and disseminate the project's findings

- as an evidence-based guide to this new form of care, incorporating specific recommendations for action
- in academic articles and lectures
- in a final research report, which we will submit to the Joint Federal Committee (G-BA).

Would you like to know more? Please contact us:

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