

PhD candidates 'Significant impact on the health of people with intellectual disability'

Project 1: Impact of Intellectual Disability (ID) physician expertise in optimizing medical care for people with ID

Aim

ID-physician (Dutch: AVG, arts voor verstandelijk gehandicapten) is, worldwide, an unique medical specialism. The aim of this project is to investigate the impact and added value of the ID physician expertise in medical care for people with ID.

Theoretical Background

People with intellectual disabilities (ID) experience health inequities. There are problems in accessing health care and obstacles in receiving appropriate care. People with ID have a considerably lower life expectancy, as they generally die 20 years earlier than the unaffected population from treatable diseases. They experience twice as many health problems compared to the general population, receive more medication, take part less in public health screening (e.g. bowel and breast cancer screening) and health promotion programmes. They are more exposed to health risk factors, such as being overweight. They have problems recognising signs of abnormality in their body, and when they do recognise these signs, they have problems describing them to health professionals. Their health needs are often not recognised. They have a pattern of morbidity that differs from the general population. General health care professionals often lack knowledge about the specific morbidity patterns of people with ID. Unlike the ID physician, they are trained during a 3-year vocational training course at Erasmus University in Rotterdam in all the aspects of medical care for people with ID. To reduce health disparities for people with ID the Dutch Minister of Health recognised medical care for people with ID as a new medical specialisation in the year 2000. Because the international interest in this medical specialism there is a need to investigate the impact and added value of the ID physicians expertise in the medical care for people with ID.

Research design

This project consists of:

- Initial literature review on the blocking mechanisms in health care for people with ID.
- Analysis of data from the ID out-patient clinic "AVG Praktijk", to explore the reasons for encounter in relation to the final diagnoses, treatments and referrals.
- Qualitative study on the experiences of people with ID and their caregivers with regard to general healthcare, and added value of the health care provided by the ID physician.
- A stakeholder analyses to explore the position of the ID physician in the medical field.

Literature

- Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Developmental Disabilities Research Reviews*. 2006;12(1):70-82.
- Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS one*. 2013;8(8):e70855.
- Heslop P, Houghton M, Blair P, Fleming P, Marriott A, Russ L. The need for FASTER CARE in the diagnosis of illness in people with intellectual disabilities. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2013;63(617):661-2.
- Straetmans JM, van Schroyensteyn Lantman-de HM, Schellevis FG, Dinant G-J. Health problems of people with intellectual disabilities: the impact for general practice. *The British journal of general practice*, 2007;57(534):64-6.

Project initiators

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Project 2: System innovations to improve health through research-practice networks in ID care

Aim

To understand roles, expectations, needs and functions within the academic collaborative in order to enhance research-policy-practice collaboration and capacity building through the development and initiation of new collaboration platforms

Theoretical Background

Academic collaboratives (AC) in which practice and policy organizations closely collaborate with academic research groups are a model frequently used in the Netherlands to support research-policy-practice collaboration and create a robust knowledge infrastructure. However, the composition, approach, results, accountability and collaboration between and within these collaboratives vary. There are significant differences between research, policy and practice that can result in blocking mechanisms in collaboration including: different timelines, different knowledge needs and priorities. These differences are important to take into account

as well as other system wide factors that can help facilitate innovations including improved collaboration. The AC 'Stronger on your own feet' (SO!) aims to improve the healthcare for people with intellectual disabilities and is a collaboration of the Radboudumc and nine ID care provider organizations. This AC is looking for innovative ways to further enhance the collaboration, learning and capacity building within the network and create platforms to share and expand academic and practical knowledge in ID health care. There are several options/platforms known from literature to reach this (i.e. communities of practice, science practitioners, digital platforms, co-creation, etc.). This project will explore what option best fits the needs and ambitions of the AC and facilitates the development and initiation of a suitable platform.

Research design

- Structured literature review on research-policy-practice collaboration
- To explore the current research-policy-practice collaboration within the AC and identify shared ambitions, ideas through group model building or other innovation systems approaches.
- Develop and implement a collaboration platform together with the members of the AC through action research.
- The platform will be continuously evaluated on factors including: how research has been applied to solve a practical problem, how the platform has created value for stakeholders, how the platform serves participants in terms of opportunities to develop expertise, create networks and build reputation.

Literature

Braithwaite, J., et al. (2009). "The development, design, testing, refinement, simulation and application of an evaluation framework for communities of practice and social-professional networks." *BMC Health Serv Res* 9. <https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-9162>

Driessen Mareeuw, F., et al. (2015). "Beyond bridging the know-do gap: a qualitative study of systemic interaction to foster knowledge exchange in the public health sector in The Netherlands." *BMC Public Health* 15(1): 1-15. <https://bmcpublikealth.biomedcentral.com/articles/10.1186/s12889-015-2271-7>

Rutter, H., et al. "The need for a complex systems model of evidence for public health." *The Lancet*. <https://www.sciencedirect.com/science/article/pii/S0140673617312679?via%3Dihub>

Wenger, E., et al. (2002). *Cultivating Communities of Practice*. Boston, Massachusetts, Harvard Business School Press.

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Project 3: Precision medicine and personalised care for chronic diseases in people with ID

Aim

To increase understanding of chronic diseases in people with intellectual disabilities (ID), and to develop precision medicine strategies in order to optimize medical care in this area.

Theoretical background

People with intellectual disabilities (ID) have more illnesses compared to people without ID, and die on average 15 to 20 years younger, often due to treatable or preventable causes. Likewise, the prevalence of chronic diseases, such as diabetes mellitus, asthma/COPD, and cardiovascular diseases in this group is higher than in the general population.

It is known that the development of diseases and presentation of symptoms is different in people with ID as compared to people without ID, due to communicative and biomedical aspects. A lack of knowledge and awareness on part of both the patient with ID as the care provider may therefore cause delay in diagnostic and treatment processes. This results in suboptimal care and poorer outcomes for people with ID. For example, retinopathy is a common risk among people with diabetes mellitus, and screening for it is recommended in certain risk groups. Whether people with ID are among those risk groups and should take part in this preventive screening is unknown. As in this example, many patterns that drive health outcomes are not as well known for the ID population as they are for the general population. This may be a contributing factor to the generally poorer health outcomes in the ID population.

Precision medicine is a concept related to the customization of health care, and include medical decisions, treatments, practices, and products being tailored to the individual patient, based on his/her own genetic, biomarker, phenotypic, or psychosocial characteristics. This project will apply the principles of precision medicine in order to personalize, and improve medical care to people with ID and chronic illness.

Research design

This project will consist of three parts:

- Detection of patterns and differences between the ID and general population.
 - a. Data from CBS, Vektis, and academic GP network
 - b. Data of medical records from ID residential care organisations.
- Identifying care pathway mismatches.
 - a. Comparing treatment plans between ID residential care organisations and general practices.
 - b. Assessing general population guidelines and their applicability to the ID population as a whole and ID subgroups
 - c. Develop strategies to deliver precision medicine to people with ID in case of chronic diseases
- Generate an ethical framework of what optimal medical to people with ID is (optional).

Literature

Mirnezami, R., Nicholson, J., & Darzi, A. (2012). Preparing for precision medicine. *New England Journal of Medicine*, 366(6), 489-491.

Morin, D., Mélineau-Côté, J., Ouellette-Kuntz, H., Tassé, M. J., & Kerr, M. (2012). A comparison of the prevalence of chronic disease among people with and without intellectual disability. *American journal on intellectual and developmental disabilities*, 117(6), 455-463.

Timmeren E, Putten A, Schroyen Lantman-de Valk H, Schans C, Waning A. Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. *J Intellect Disabil Res* 2016;60(11):1109-18

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Project 4: Expanding availability of healthcare innovations for people with ID: exploring e-health applications to improve health

Aim

To gain knowledge on available e-health and its applications in healthcare for people with ID, and to develop a practical guide to support ID care facilities in choosing appropriate e-health applications, using them effectively and evaluating their added value for health of people with ID.

Background

The development of technologies for health care known as e-health has a great potential impact on health and healthcare delivery. E-health includes all applications of information and communication technologies to support and promote the prevention, diagnosis, treatment and monitoring of diseases and management of health. These technologies are demonstrating effectiveness in a variety of applications in the general population. People with intellectual disabilities (ID) form a group of special interest, as they have a higher prevalence of health problems than the general population and they experience different health needs that are often unrecognized. People with ID do not notice or discuss unusual health signs, and regular health measurements are not always feasible in this group or are considered too burdensome. E-health offers important opportunities to monitor health and physical conditions in this vulnerable group, facilitating detection of health problems and reducing delays in diagnosis or treatment.

In the expanding and constantly changing field of e-health, appraisal is crucial to select relevant e-health applications for health monitoring and to integrate them into ID care facilities. Nevertheless, little is known about the use of e-health in people with ID in general and health monitoring technologies in particular. The majority of studies examining the use of e-health in this group refers to supporting instrumental activities of daily life.

This project explores which e-health innovations are available and relevant for health monitoring in this patient group and how ID care facilities can make responsible choices for an efficient use of these innovations. Based on the knowledge gained a practical guide will be developed that supports ID care facilities in doing so.

Research design

The project will consist of:

- Inventarisation of available health monitoring technologies, and the added value of the use of the technologies for people with ID
 - a. Literature review
 - b. Interviews with experts and end-users, eg. patients, their families and care providers in ID care.
- Development of a practical guide for inclusive and responsible innovation in ID healthcare practice
- Practical application of one selected monitoring technology.
 - a. Feasibility study
 - b. Validation study; the psychometric properties of the e-health application in people with ID are determined.

Literature

Vázquez A., Jenaro C., Flores N., Bagnato M.J., Pérez M.C., Cruz . E-Health interventions for adult and aging population with Intellectual Disability: A Review. *Front Psychol.* 2018;9:2323.

van Schrojenstein Lantman-de Valk, H. & Walsh, P.N. Managing health problems in people with intellectual disabilities. *BMJ* 2008;337:a2507

Vukovic V., Favaretti C., Ricciardi W., de Waure C. Health technology assessment evidence on e-health/m-health technologies: evaluating the transparency and thoroughness. *Int J Technol Assess Health Care.* 2018;34:87-96.

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Project 5: Cancer care for people with intellectual disabilities

Aim

To gain insight in current cancer diagnostic and treatment characteristics among people with ID and in differences compared to the population without intellectual disabilities.

Theoretical background

Increasingly international studies raise the concern for under-diagnosis and impaired access to cancer care for the ID population. There have been reports of poor uptake of cancer screening, detection of cancer at a higher tumour stage, a different pattern of cancer distribution across affected organs, and differences in cancer-related mortality rates. We have estimated that per year more than 22,600 Dutch ID people require some type of cancer care. Although the size of the Dutch ID population affected by cancer is substantial, very little is known about the inequalities in cancer care, nor about the specific cancer care needs of the ID population at large. This lack of knowledge prevents delivery of appropriate cancer care for people with ID, while similar opportunities for appropriate cancer care should be provided.

Research design

The project will consist of three parts.

- Literature review of knowledge about ID syndromes and cancer development and an assessment of how this knowledge is currently represented in syndrome guidelines.
- Data research with cancer registry data (IKNL). Using population-based data at the individual level, cancer incidence rates will be analysed. Specific variables of interest will be tumour stage at diagnosis, primary treatment, and cancer specific mortality rates.
- Interviews or focus group study with cancer care providers and ID physicians to explore current opinions about cancer care to people with ID and barriers experienced in the treatment of cancer in people with ID. Dependent of the background and interest of the candidate, ethical concerns related to cancer treatment in the ID population can be included as well.

Literature

Hogg, J., & Tuffrey-Wijne, I. (2008). Cancer and Intellectual Disability: A Review of Some Key Contextual Issues. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 509-518. doi:10.1111/j.1468-3148.2008.00422.x

Merten, J. W., Pomeranz, J. L., King, J. L., Moorhouse, M., & Wynn, R. D. (2015). Barriers to cancer screening for people with disabilities: A literature review. *Disability and Health Journal*, 8(1), 9-16. doi:10.1016/j.dhjo.2014.06.004

Wyatt, D., & Talbot, P. (2013). What knowledge and attitudes do paid carers of people with a learning disability have about cancer?. *European journal of cancer care*, 22(3), 300-307

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