

## University of Groningen

### **Dementia symptoms in persons with severe/profound intellectual disability: Expertise of practice**

Waninge, A; Wissing, Maureen; Hobbelen, Hans; Fokkens, Andrea; Dekker, Alain D.; De Deyn, Peter

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*

Publisher's PDF, also known as Version of record

*Publication date:*

2021

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Waninge, A., Wissing, M., Hobbelen, H., Fokkens, A., Dekker, A. D., & De Deyn, P. (2021). *Dementia symptoms in persons with severe/profound intellectual disability: Expertise of practice*. 1214-1215. Abstract from IASSIDD Europe Congress, Netherlands.

**Copyright**

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

**Take-down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

education requires a lot of planning and cooperation. The teachers and school staff give knowledge and support to youth with intellectual disabilities to make informed choices of adult life and of parenthood.

### Online learning & COVID-19: Exploring experiences of Canadian adolescents with Down syndrome

Lynn Levatte<sup>1</sup>, Natasha Bellows<sup>2</sup>

<sup>1</sup>Cape Breton University, Sydney, Canada; <sup>2</sup>McGill University, Montreal, Canada

**Background:** COVID-19 has impacted the education delivery of students across the globe. Many students, especially those with intellectual disabilities, such as Down syndrome have experienced additional barriers. The pandemic has forced many schools to close temporarily and offer online platforms for education delivery.

**Method:** This qualitative study aimed to explore the online learning experiences of adolescents with DS who participated in a 16-week introductory online learning project. Participants included middle or high school students, with a diagnosis of Down syndrome who lived in an Atlantic Canadian province.

**Results:** Initial evidence collected revealed that students with Down syndrome received limited online learning opportunities or support from the public school system during COVID-19 and had received very little or no transition planning for changes in education program delivery. Additionally, it was noted that participants in the study gained independence and confidence for operating technology, demonstrated enhanced communication skills and displayed increased social skill development.

**Conclusions:** Although situated in Canada, the implications from this study may be readily applied to organizations engaged in online learning initiatives for students with Down syndrome across the globe.

### The relation to writing of two students with autism spectrum disorder

Marie-Eve Boisvert<sup>1</sup>, Delphine Odier-Guedj<sup>2</sup>

<sup>1</sup>University of Montreal, Montreal, Canada; <sup>2</sup>HEP Vaud, Lausanne, Switzerland

**Background:** To improve writing teaching practices for students with autism spectrum disorder in an inclusive education setting, it is instructive to examine writing difficulties from a strength-based perspective by augmenting their voice on writing. To do so, this study explores the relation to writing of teenagers with autism spectrum disorder.

**Method:** Writing activities of two 14-year-old students with autism spectrum disorder in inclusive settings and out of school were collected through ethnographic interviews (four per participant) and filmed observations in classes and home 12 hours and 45 minutes per participant) over six months. Qualitative analyses were performed and the data from both sources were cross-referenced.

**Results:** This study found a diversity of writing skills, shedding a different light on what might be considered writing difficulties for teenagers with autism spectrum disorder. It also identified what motivated the participants to engage positively in writing activities in a variety of contexts.

**Conclusions:** The findings underline the richness of information that we can collect by listening to the voices of students, highlighting levers of action to support student engagement in writing activities. Results also point to bridges that might be built between writing in various contexts and the importance of social interaction through writing.

### A systematic review of music education studies and disability: Results, omissions and opportunities

Ross Walker<sup>1</sup>

<sup>1</sup>University of Queensland, St. Lucia, Australia

**Background:** Music training is touted as capable of delivering many benefits to learners. These benefits should be available to students with intellectual and developmental disabilities. However, a systematic review of the literature suggests that they are not.

**Method:** A systematic quantitative literature review searched music and education journals for original research that had investigated music education and intellectual and developmental disabilities. Studies that had described music's use and function in inclusive classrooms since 2000 were analysed.

**Results:** In music-education research, surprisingly few studies explore ordinary groups of children in inclusive classrooms. The results revealed that while children with intellectual and developmental disabilities are most likely present in regular classrooms, disability is rarely considered. When it is, it is almost always as a disability-specific study that fails to reveal insights into inclusive educational practices.

**Conclusions:** This systematic literature review has identified significant gaps in music education research which, in turn, impact the inclusion of students who have intellectual and developmental disabilities in mainstream music classes. Implications for both the inclusive music education of students with intellectual and developmental disabilities, and for reconceptualising future research, are considered.

## Track 1b Aging/End of Life

### PRESENTATIONS IN A SYMPOSIUM

#### *Dementia in people with severe/profound intellectual disabilities*

#### **Dementia symptoms in persons with severe/profound intellectual disability: Expertise of practice**

Aly Waninge<sup>1</sup>, Maureen Wissing<sup>2</sup>, Hans Hobbelen<sup>1</sup>, Andrea Fokkens<sup>3</sup>, Alain Dekker<sup>2</sup>, Peter De Deyn<sup>2</sup>

<sup>1</sup>Hanze University of Applied Sciences Groningen, Groningen, The Netherlands; <sup>2</sup>Department of Neurology and Alzheimer Center, University of Groningen, Groningen, The Netherlands; <sup>3</sup>Department of Practice-oriented Scientific Research (PWO), Alliade Care Group, Heerenveen, The Netherlands

**Background:** In people with severe or profound intellectual disabilities, it is difficult to diagnose dementia. As timely identification and diagnosis of dementia allows for a timely response to changing client wishes and needs, this study aims to examine symptoms, and diagnosis of dementia in practice.

**Method:** Family members and professionals were invited to fill out a survey about symptoms and diagnosis of dementia in people with severe or profound intellectual disabilities. Results of the survey were further explored within semi-structured interviews with professionals having experience with signaling and diagnosing dementia in these people. Symptoms found in the survey and transcripts of the interviews were qualitatively analyzed, using thematic analyses based on a developed symptom-matrix.

**Results:** The survey was filled out completely by 14 family members and 90 professionals with different backgrounds. Results showed that behavioral changes were recognized more frequently than cognitive decline. Compared to those without dementia, epilepsy and motor decline were more present in case of dementia. Fifteen interviews (until saturation) with professionals provided an in-depth view into the symptoms, and how to identify them, again stressing behavioral alterations and to a lesser extent cognitive symptoms.

**Conclusions:** Comprehensive results about specific symptoms will be presented during the congress.

#### Focus group research into relevance, symptoms and training needs

Alain Dekker<sup>1</sup>, Maureen Wissing<sup>2</sup>, Aurora Ulgiati<sup>1</sup>, Bas Bijl<sup>3</sup>, Gaby van Gool<sup>4</sup>, Marieke Groen<sup>3</sup>, Esther Grootendorst<sup>4</sup>, Ina van der Wal<sup>1</sup>, Hans Hobbelen<sup>5</sup>, Peter De Deyn<sup>2</sup>, Aly Waninge<sup>6</sup>  
<sup>1</sup>Alliade Care Group, Beetsterzwaag, The Netherlands; <sup>2</sup>University Medical Center Groningen, Rijksuniversiteit Groningen, Groningen, The Netherlands; <sup>3</sup>Heeren Loo, Amersfoort, The Netherlands; <sup>4</sup>Ipse de Bruggen, Zwammerdam, The Netherlands; <sup>5</sup>Hanze Hogeschool, Groningen, The Netherlands; <sup>6</sup>Royal Dutch Visio, Vries, The Netherlands

**Background:** In people with severe or profound intellectual and multiple disabilities, it is difficult to differentiate dementia from their pre-existent baseline level of functioning. Moreover, studies on observable dementia symptoms are scarce. Therefore, this study examined the 1) relevance of dementia diagnosis in severe or profound intellectual disabilities, 2) observable symptoms and 3) training/information needs.

**Method:** Four explorative focus group sessions were held with 12 to 13 participants each (care professionals and family members) who had experience with people with severe or profound intellectual and multiple disabilities ( $\geq 40$  years) and decline/dementia. Using thematic analysis, categories and (sub)themes were identified in the transcripts.

To answer research question 2, symptoms mentioned were categorized using a symptom matrix.

**Results:** Thematic analysis showed that participants wanted to know about the diagnosis of dementia for a better understanding and to be able to make informed choices (question 1). Using a symptom matrix, cognitive and behavioral changes were shown to be the most prominent (question 2). Participants also indicated that they needed enhanced training, more knowledge development and translation, and supportive organizational choices/policies (question 3).

**Conclusions:** Timely identification and diagnosis of dementia allows for a timely response to changing client wishes and needs. This requires a better understanding of the symptoms.

#### A systematic literature review of observable symptoms

Maureen Wissing<sup>1</sup>, Aurora Ulgiati<sup>1</sup>, Johannes Hobbelen<sup>2</sup>, Peter De Deyn<sup>1</sup>, Aly Waninge<sup>2</sup>, Alain Dekker<sup>1</sup>

<sup>1</sup>University Medical Center Groningen, Groningen, The Netherlands;

<sup>2</sup>Hanze University of Applied Sciences, Groningen, The Netherlands

**Background:** Life expectancy of people with severe or profound intellectual disability increases, which contributes to the risk of developing dementia. However, early detection and diagnosing dementia is complex, because of their low-level baseline functioning. Therefore, the aim is to identify observable dementia symptoms in adults with severe or profound intellectual disability in available literature.

**Method:** A systematic literature search, in line with PRISMA guidelines, was conducted in PubMed, PsycINFO and Web of Science using a combination of search terms for severe or profound intellectual disability, dementia/aging and aged population.

**Results:** In total, fifteen studies met inclusion criteria. Cognitive, behavioral and psychological symptoms (BPSD) and a decline in the ability to perform activities of daily living as well as neurological and physical changes were found. This presentation gives an overview of reported symptoms of (possible) dementia-related symptoms in severe or profound intellectual disability.

**Conclusions:** Despite growing attention for dementia in people with intellectual disabilities in literature, only very few studies have studied dementia symptoms in severe or profound intellectual disability. Given the complexity of signaling and diagnosing dementia in SPID, dedicated studies are required to unravel the natural history of dementia in severe or profound intellectual disability, specifically focusing on observable symptoms for caregivers of (early) dementia in this population.

#### Older adults with intellectual and developmental disorders

##### Evaluating dementia capability of service systems for people with intellectual and developmental disorders and dementia

Christine Clifford<sup>1</sup>, Emily Lauer<sup>1</sup>