



E-Health: 'I feel in control of my life'

Exploring innovative forms of support through inclusive research

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Background and objective

Services for people with intellectual disabilities (ID) increasingly use E-health applications such as Telecare¹. In the Netherlands, service provider Philadelphia Care Foundation implemented the E-health innovation 'DigiContact' as part of their support packages².

DigiContact is a videoconferencing program. Users can contact specially trained support professionals 24/7. It is aimed at promoting independence and community participation of adults with ID who live independently in their own homes. We explored experiences users have with DigiContact.

The objective highlighted in this poster is to create insights into the support provided by DigiContact.

Methods

- This study is part of an inclusive research project. A researcher worked together with a co-researcher who was a client of DigiContact.
- The co-researcher interviewed 21 DigiContact users.
- Analyses were performed with MAXQDA 12. A creative analysis session³ was held to analyze and interpret results with three self-advocates with ID.
- Results concerning the provided support were classified according to the five dimensions of the AAIDD conceptual framework of human functioning⁴ (Figure 1).

Interview respondents (N=21):

- Characteristics: 62% men; median age 45 (range 31-61).
- Living situation: alone (n=11); with partner (n=8); with parent(s) (n=2).
- DigiContact frequency: weekly and scheduled (n=14, of which 4 also called in unplanned); daily and scheduled (n=1); once every couple of months unscheduled (n=4); variable (n=1); unknown (n=1).
- Additional support: support worker visiting at home (n=15); support worker at meeting point (n=6).

Results

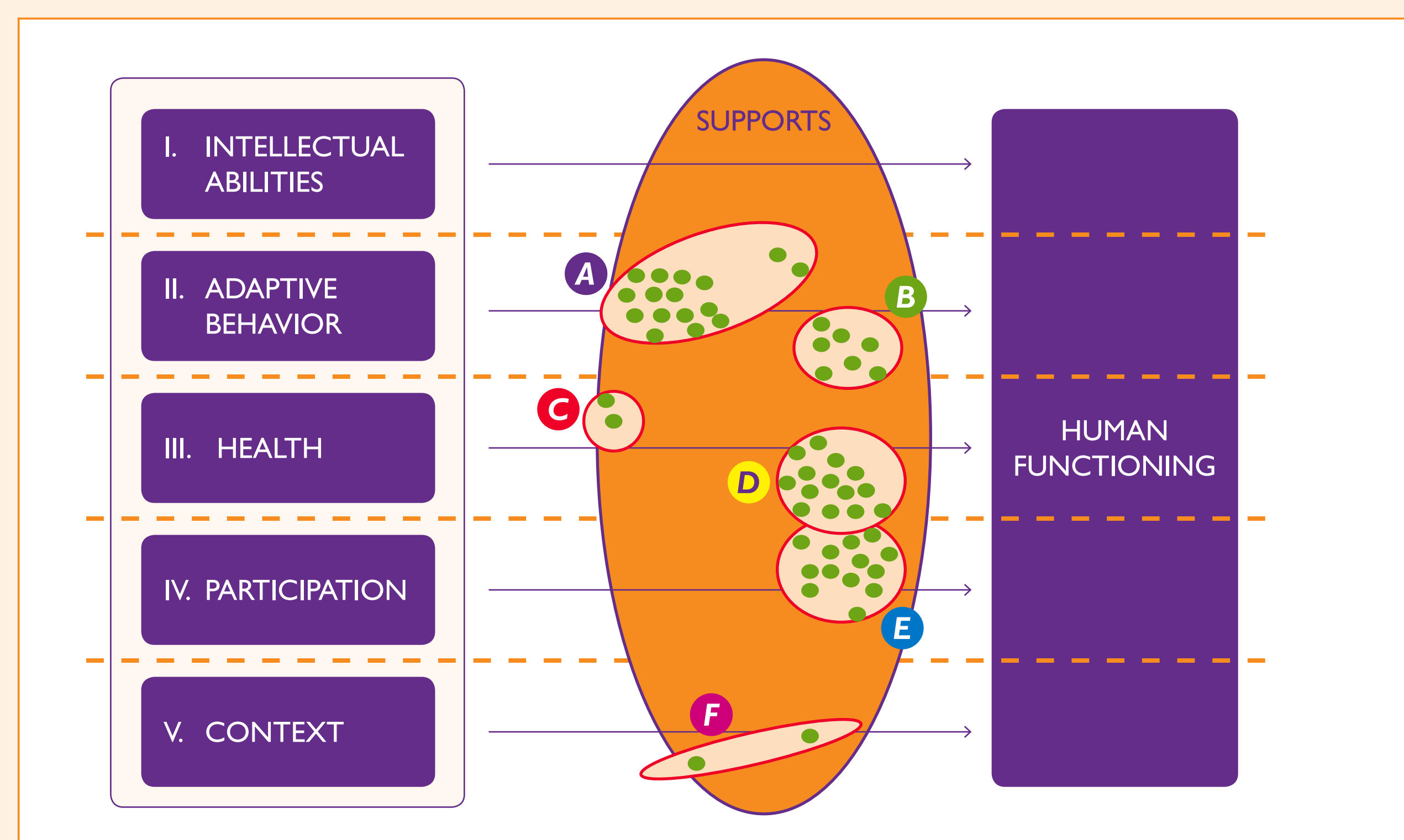


Figure 1: DigiContact support classified according to AAIDD conceptual framework of human functioning

DigiContact support:

- A Practical and conceptual skills**
 - Administration, mail, finances
 - Plan daily/weekly schedules
 - Prepare travel plans (public transport)
 - Prepare contacts with healthcare professionals
- B Social skills**
 - Social conflicts (at work, with partner, parents, friend etc)
 - Coaching assertiveness
- C Physical health**
 - Advice on what to do in case of experiencing pain
 - Reminder of medication intake
- D Mental health**
 - Telling your story to clear ones head of worries, stress and frustrations
 - Preventing problems (aggression, alcohol abuse) by releasing tension frequently
 - Advice on how to deal with (intense) emotions
- E Participation**
 - Connecting with someone for small talk, sharing experiences
 - Assistance in searching for a buddy
- F Context**
 - Monitoring and promoting change towards healthy (eating) habits
 - Provide in frequent need for confirmation coming from insecurity

Reflection

Two themes emerge from the stories of DigiContact users about the support they receive:

- Social problem solving, recurring conflicts in relationships with others, having a small or inaccessible social network and the occurrence of emotional or mental health problems.
- Learning new things, problem solving and the (increasing) complexity of societal demands.

Inclusive research, richer results!

We noticed many respondents experiencing relieve and feeling more at ease, as they perceived the interviewer was 'one of them'. This facilitated them to talk more freely and to elaborate on their experiences more. Because of this we felt that the inclusive character of the interviews generated richer results.

We advise to use an inclusive research design and specifically a co-researcher with ID when people with ID are subject of research.

References

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- ⁴ Schalock, R.L., Borthwick-Duffy, S.A., Bradley, V.J., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., et al. (2010). *Intellectual disability: Definition, classification, and systems of supports*. Washington, DC: American Association on Intellectual and Developmental Disabilities.