ieder(in)















Our story



- 1. The initiative 'Dementia Table sharing and improving'
- 2. Short movie
- 3. Involvement of relatives and caregivers
- 4. The success of the Dementia Table in The Netherlands



1.'Dementia Table – sharing & improving'



'Dementia Table – sharing and improving' is a project of ieder(in)
 leder(in)

Ieder(in) (Everyone in) is an umbrella organisation in The Netherlands for people with a physical disability, intellectual disability or chronic illness. Two hundred and fifty organisations are affiliated to Ieder(in). They represent the interests of more than two million people

 The Dementia Table project is initiated by KansPlus, an interest group for people with intellectual disabilities and their relatives



Other meaningful interest groups support the project,
 like the Dutch Alzheimer Association



We are...

- Sandra Overbeek
- Charlotte Thoolen



Buro Opaal is a small organisation for easy and accessible information and communication

We manage the initiative Dementia Table – sharing & improving

What is a Dementia Table?



- Initiative for sharing & improving knowledge about ageing and dementia of people with intellectual disabilities
- For family members and (professional) caregivers of people with intellectual disabilities

Assen



Purpose of a Dementia Table



- A place where family, family caregivers, professional caregivers can have a conversation about people with an intellectual disability who are getting older and have dementia
- In an open and relaxed atmosphere they can exchange knowledge about care and support and learn from each others questions
- Signals and unanswered questions can be further examined and elaborated afterwards

Structure of the Dementia Table



- accommodation accessible and approachable
- warm welcome with drinks and bites
- one topic to talk about
- an accessible method to introduce the topic
- lots of room for discussion and meeting
- a good moderator to guide the attendants
- tight time monitoring
- evaluation

2. Short movie



Purpose of the Project



- In three years time organize a Dementia Table in each province of The Netherlands (12)
- Together with care organisations, local authorities an relatives
- The project provides in one first try-out to examine (evaluate) if this is a suitable form of exchanging knowledge for family and caregivers
- Afterwards make an agreement with the care organisations and local authorities to continue the Dementia Table
- Give tips about the way to organize and finance the Dementia Table
- Tips and previous experiences are collected in a reader and on a website

Angerlo



3. Involvement of relatives and caregivers



- People with an intellectual disability are getting older. The chance that they get dementia, is increasing. People with Down syndrome often have to deal with the decease Alzheimer already from the age of forty
- The process from getting ill to death can go fast and is very drastic.
 For the individual person but also for the surrounding people
- Relatives want to share their experiences with other relatives. They
 also want information about for example responsibility, safety and
 care



- Caregivers can give information and they can learn from the questions and experiences of relatives
- Care organizations and local authorities can help to find relatives and caregivers of people with an intellectual disability and dementia
- It's important that relatives and caregivers examine the Dementia
 Table as a method of support

Vught



4. The success of the Dementia Table in The Netherlands



- There have been organised first Dementia Tables in 9 different provinces in The Netherlands
- In most of these provinces there have already been follow-ups
- After this summer the first Dementia Table will take place in the three last provinces. Amongst them: Groningen
- Professor Peter Paul De Deyn and Alain Dekker from the University Medical Center Groningen(UMCG) participate in the working group Dementia Table Groningen

Veldhoven



Results 1



- Many family and professional caregivers attended the first Dementia Tables (range 20 to 70)
- Most of the time there where as many family members as caregivers
- The participants made a lot of conversation
- Participants are enthusiastic: family, family caregivers as well as professional caregivers
- The first topic to talk about: 'getting older, dementia and people with intellectual disabilities' or 'how to deal as family and caregivers together with dementia and people with intellectual disability'
- To introduce the topic, we used: film, theatrical performance, interview with a relative and a caregiver, presentation

Borne



Results 2



- At the end of each Dementia Table participants fill in an evaluationpaper. This gives a lot of information for follow-ups
- Some of the new topics named by participants:
 - books about life
 - information about dementia
 - methods of support
 - palliative care
 - people with severe intellectual disabilities and dementia
 - housing

Delft



Follow-up 1



 The members of the working group come to an agreement with each other about how to continue the Dementia Table

For example:

- all the involved care organizations decide to organize the follow-ups and donate the money and further investments
- the local authority decides to invest in the Dementia Table, they should provide guidance for people with a disability and there caregivers (Social Support Act)
- other (local) funds support the Dementia Table financially

Follow-up 2



- In each province there will be an 'ambassador': someone who coordinates the Dementia Tables en gives information
- Signals and unanswered questions will be further examined and investigated > together with scientists of Dutch university's

Geleen



Thank you for listening!



- ■The Dementia Table will be organized in each province of the Netherlands. On the website http://www.iederin.nl you can find more information about this project.
- This project is made possible by financial support of the Fund Intellectual Disabled, Rabobank Foundation, Foundation SPZ en the VGN in the Netherlands.
- ✓ <u>www.kennispleingehandicaptensector.nl/gehandicaptenzorg/</u> <u>Dementietafels-dementie-verstandelijke-beperking</u>
- √ www.iederin.nl