UNECE Policy Meeting on Ageing: Local Alliances for people with Dementia in Germany

Dr. Anneli Rüling, Geneva 20 Nov., 2019
Development of a National Dementia Strategy

Responsibility: Health Ministry, Ministry for Family, Older Persons, Women and Youth and Ministry for Education and Science

Background: Agenda „Cooperation for People with Dementia“, Report 9/2018,
Experience from Programme „Local Alliances for People with Dementia“ (2012-2018)

Partners: Alzheimer Society, Länder (federal states), Local Authorities, welfare agencies, social insurances, churches, stake holders in health and long term care policy

Targets: Better quality of life and participation in social life for People with Dementia and support for the informal carers, good medical treatment and prevention, high quality research.

Timeline: Start: End of 2018, End: Summer 2020, Kick-off is scheduled in June 2020

Working Groups:
1) Better participation of people with dementia at the local level
2) Supporting People with Dementia an their relatives
3) Better medical tretment and Care for people with Dementia
4) Funding excellent research
Local Alliances for people with Dementia

- Programme 2012-2018: 500 Local Alliances were established
- Funding: 10,000 € over 2 years
- Only 146 counties are not covered by the programme
- Research completed: 15 case studies, 1 online survey of organisations (42% return rate)

Research Questions:
- Area of activity
- Structure of the network, cooperation with local authority
- Groups targeted through activities and accessibility of the groups
- Resources of the network, level of volunteer involvement
- Sustainability of the networks after the end of funding
Areas of activity of Local Alliances

Which kinds of action did the local alliance take? (n=219)

- Information: 81%
- Public Relation: 77%
- Network building: 75%
- Development of (new) activities and courses: 73%
- Training: 56%
- Design of public space: 17%
- Better patient-centered care: 18%
Actors reached by cooperation

How well were the could the addressed actors be reached?

- Professionals in Care institutions (n=98)
  - Reached to a large extend: 70
  - Reached to a small extent: 29
  - Not reached: 0
  - Don't know: 0

- Relatives/ Neighbours/ Friends (n=190)
  - Reached to a large extend: 65
  - Reached to a small extent: 30
  - Not reached: 5
  - Don't know: 0

- Education Organisations (n=59)
  - Reached to a large extend: 48
  - Reached to a small extent: 51
  - Not reached: 0
  - Don't know: 0

- General Public (n=150)
  - Reached to a large extend: 45
  - Reached to a small extent: 45
  - Not reached: 0
  - Don't know: 0

- Politics /Administration (n=81)
  - Reached to a large extend: 45
  - Reached to a small extent: 46
  - Not reached: 0
  - Don't know: 0

- People with dementia (n=158)
  - Reached to a large extend: 37
  - Reached to a small extent: 54
  - Not reached: 0
  - Don't know: 0

- Public actors (n=86)
  - Reached to a large extend: 28
  - Reached to a small extent: 63
  - Not reached: 0
  - Don't know: 0

Legend:
- Reached to a large extend
- Reached to a small extent
- Not reached
- Don't know
A bar chart showing the percentage of trainings offered for different categories:

- Trainings for Relatives: 69%
- Trainings for Volunteers: 74%
- Trainings for Professionals in Care/ Medical Professions: 66%

The title of the chart is "Actors reached through training."
Impact of Local Alliances on the activity at local level

Development of activities at local level

- Information and Training Courses: 26 existed before LA, 14 extended without LA, 57 extended through LA, 3 reduced, 3 ceased to exist
- Offer for participation: 23 existed before LA, 19 extended without LA, 54 extended through LA, 4 reduced, 4 ceased to exist
- Dementia Guidebook: 31 existed before LA, 11 extended without LA, 43 extended through LA, 13 reduced, 7 ceased to exist
- Advisory Service: 43 existed before LA, 15 extended without LA, 40 extended through LA, 3 reduced, 3 ceased to exist
- Self-help groups: 32 existed before LA, 22 extended without LA, 40 extended through LA, 4 reduced, 4 ceased to exist
- Voluntary help: 32 existed before LA, 22 extended without LA, 40 extended through LA, 4 reduced, 4 ceased to exist
- Centralised agency at local level: 42 existed before LA, 20 extended without LA, 31 extended through LA, 7 reduced, 7 ceased to exist

Legend:
- existed before the Local Alliance
- extended without connection to LA
- extended through activities of LA
- reduced
- ceased to exist
Situation of relatives/carers

- Could best be reached through low-threshold offers (information in drug stores)
- The trainings were also adequate means to reach relatives
- High level of stigmatization, especially in rural areas make it difficult to sustain more sophisticated measures

⇒ Difficult to sustain self-help groups
⇒ Need for more direct help and advisory „Dementia Care Management“
⇒ Need for voluntary support
Conclusions for policy development

- Despite little funding, sustainable networks have developed in many cases
- Networks are more sustainable if supported by the local authorities
- Networks give valuable contributions to the development of “caring communities”
- Voluntary work in the field has risen, however it requires coordination
- Relatives need more low-threshold offers and guidance
- Requirement for more awareness raising in the general public
- Linking up of different services: medical and care services should cooperate more with civil society networks and local authorities
Thank you for your attention!

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