




# 'Ageing in place' for people with disabilities

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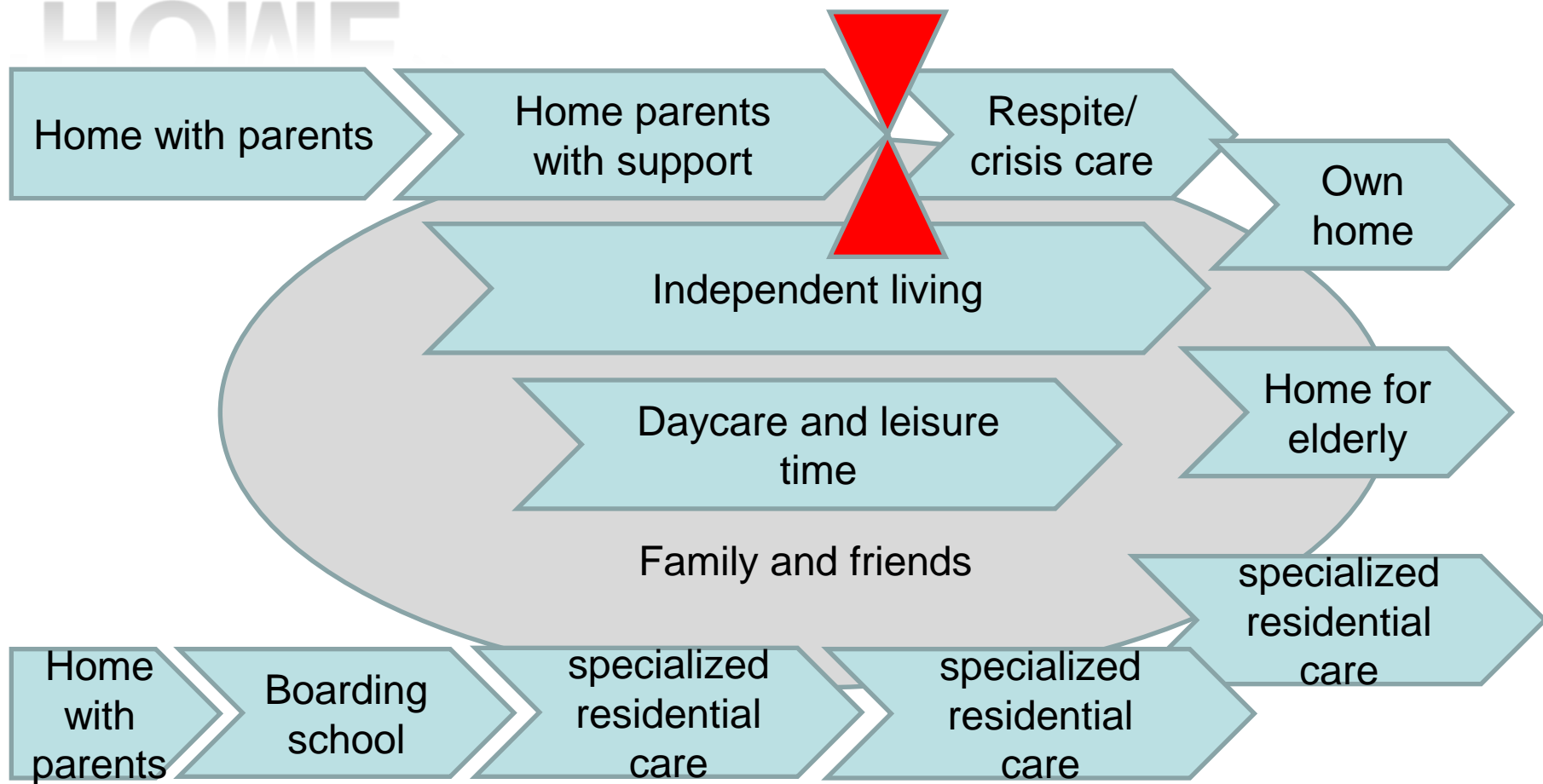
Ageing in place:  
'Allowing the elder to remain in the living situation of their choice for as long as they wish and are able to' (Bigby, 2004)

Bigby, C. (2004). *Ageing with a lifelong disability. A guide to practice, program and policy issues for human services professionals*. London: Jessica Kingsley Publishers.





**“HOME”** has many meanings... there are several life course 'pathways'



# Ouder

worden met een  
verstandelijke beperking

Een gids voor cliënten, mantelzorgers en hulpverleners



# Flemish Information brochure

# Themes in the brochure

- Worrying about the future
- So much work
- Staying active
- Family matters
- Crisis
- What now?
  - independent living
  - Moving in with family
  - Care and rest in the neighbourhood
  - Residential care
- Towards the end of life

## 50+ people on care waiting list in Flanders (2007)

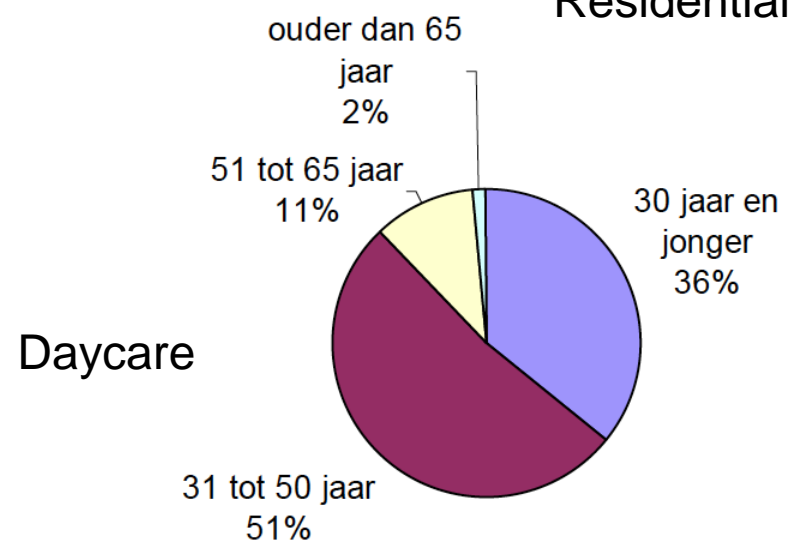
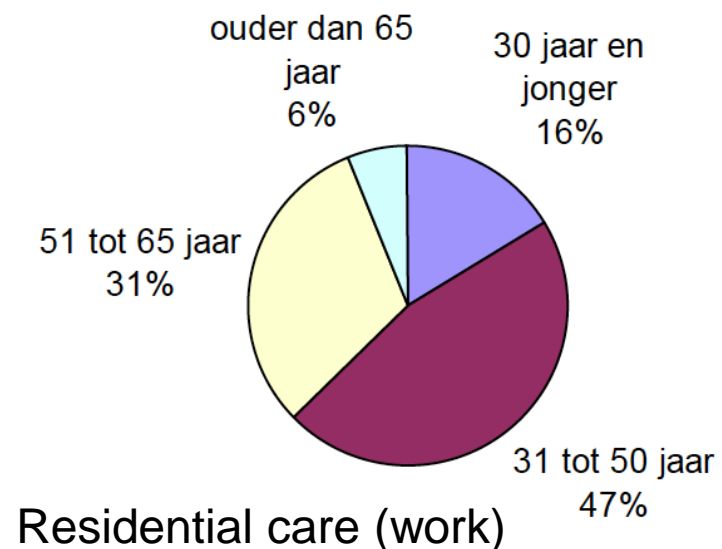
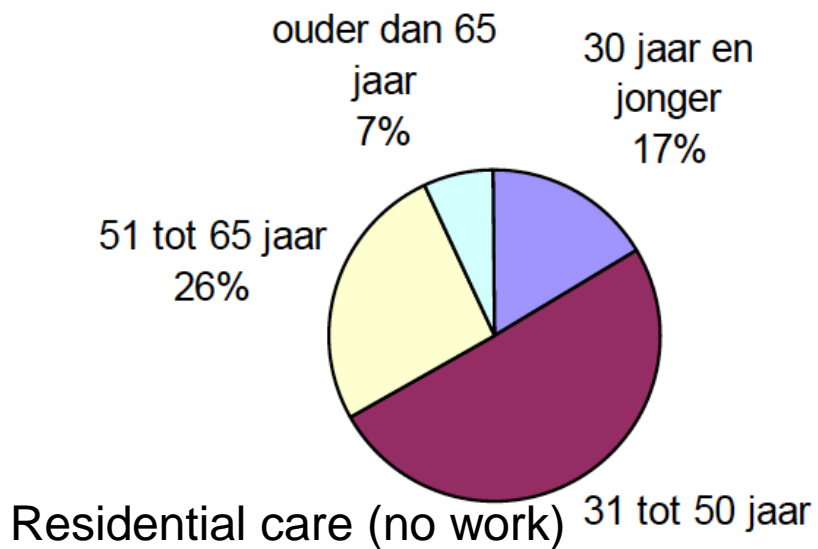
### Waiting list for specialized care 2007

"Waiting listt"	50-59			60-...			
	UC1	UC2	UC3	UC1	UC2	UC3	
<b>Daycare</b>	55	29	35	28	10	13	170
<b>Daycare/Supported work</b>	9	7	5	2	2	1	26
<b>Assisted living</b>	100	49	37	25	13	14	238
<b>Shared housing</b>	27	25	25	10	11	4	102
<b>Residential care (work)</b>	17	13	20	4	1	7	62
<b>Nursing home</b>	110	76	60	70	47	50	413
<b>Activity</b>	108	74	96	76	47	75	476
<b>Independent Living</b>	22	15	22	7	4	14	84
<b>Home-support foster care</b>	78	1	1	57	3	1	141
<b>Assisted living (fostered)</b>	1	3	2	3	0	0	9
	5	3	1	6	1	0	16
	532	295	304	288	139	179	<b>1737</b>



partners in  
Hogeschool-Universiteit Brussel

# Current situation (Multi-annual analysis, 2010-2014 Flanders – Belgium)





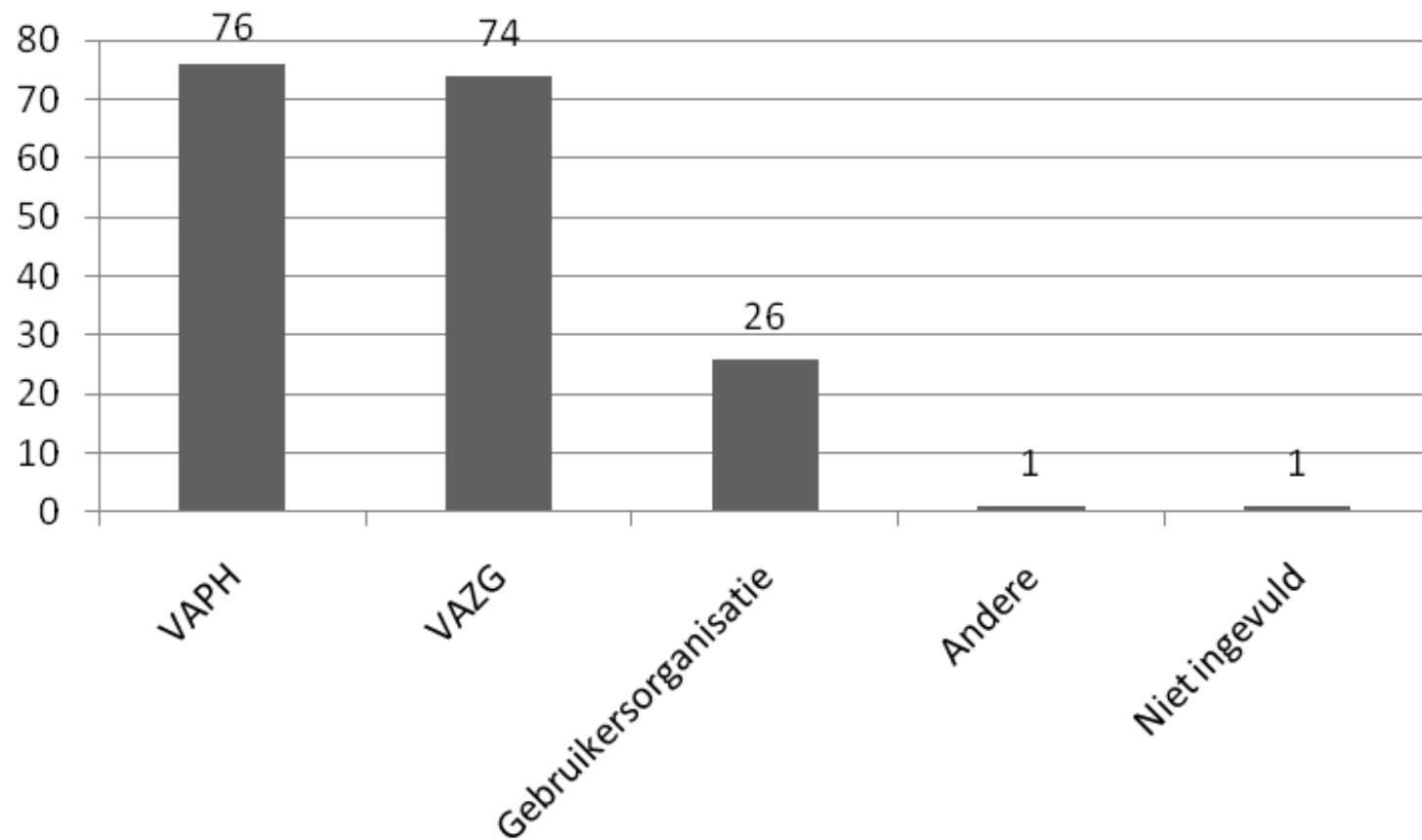
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# Desirableness/feasibleness of future care/support services (delphi-study)

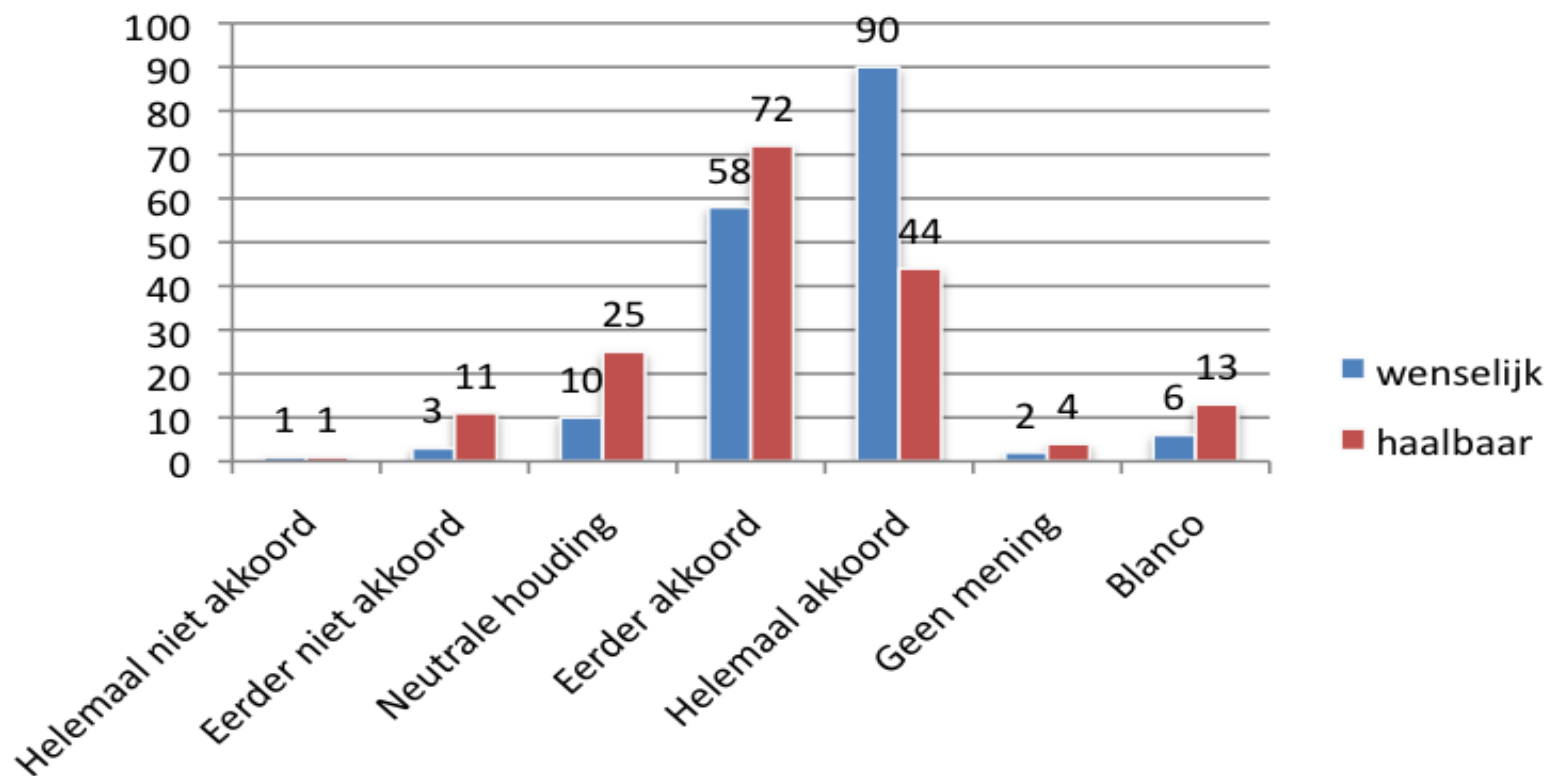
# Research paper 'Caring for quality of life' ordered by Flemish ministry of Welfare (2010)

- European chapter:
  - European countries put more emphasis on informal care, caregiving, due to lack of specialized care.
  - The financial means to give an income to elderly and people with disabilities are situated on the same political level and in the same departements in many countries, which makes decision making easier than in Belgium
  - Lack of qualified personnel, undeclared work in informal care
- Flemish chapter:
  - Overview care services for elderly and people with disabilities
  - Delphi-research feasibility and desirability policy options (N=170)

# Survey practitioners disability care and regular (elderly) care (2010)



(“To support ageing people with disabilities, it is feasible/desirable that the two welfare departments 'elderly' and 'disability' **need to co-operate**)



## Joint opinion across groups

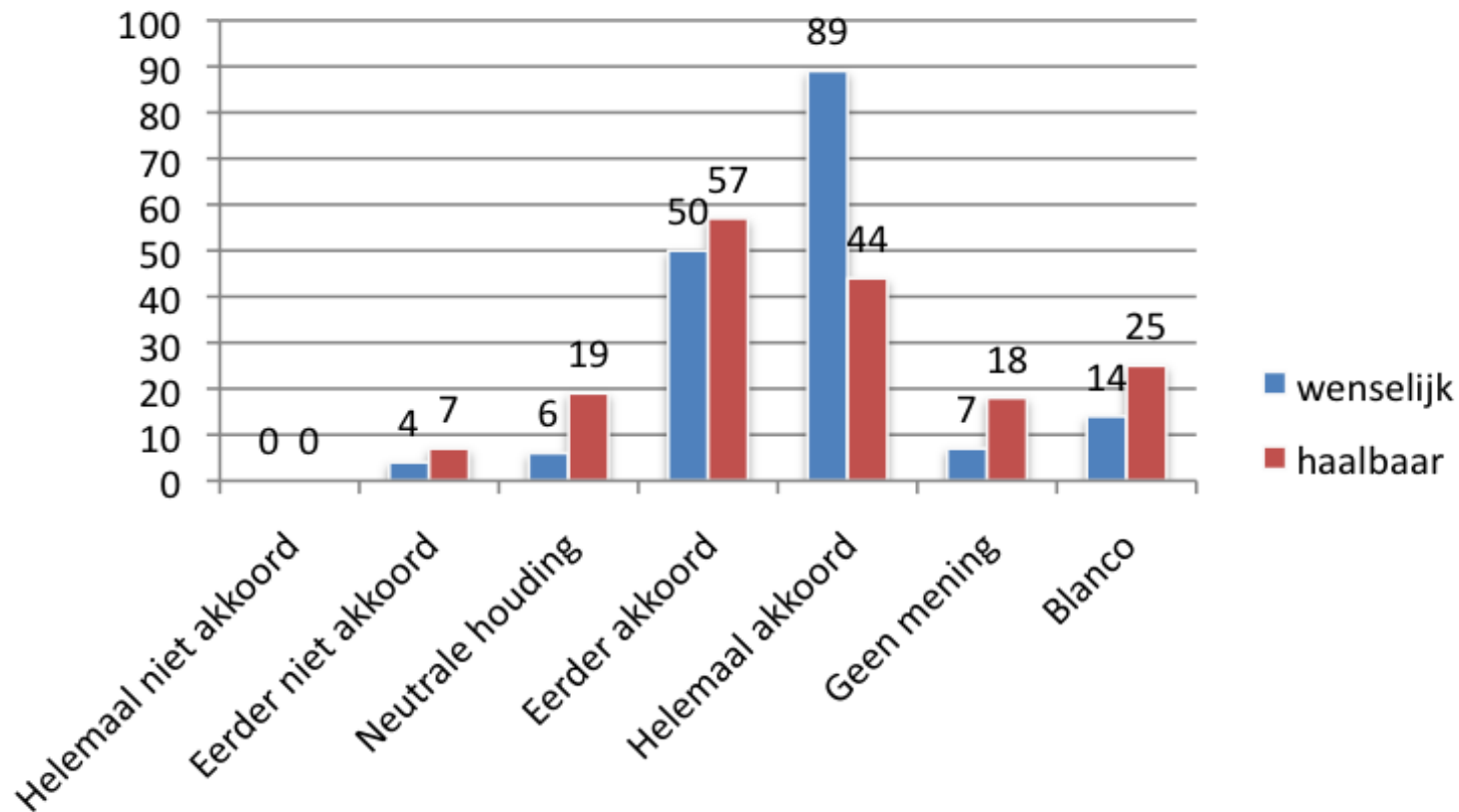
	Desirability M (SD)	Feasibility M (SD)
<b>COOPERATION BETWEEN SECTORS</b>	4,44 (0,75)	3,96 (0,90)
organize daily activities together	3,76 (0,97)	3,74 (0,97)
integrated case management	4,02 (0,88)	3,75 (0,97)
organize help on call together <sup>a</sup>	3,92 (0,96)	3,75 (0,90)
exchange of knowledge/knowhow <sup>b</sup>	4,64 (0,61)	4,37 (0,70)
Regional consultation about bottleneck - cases	4,22 (0,87)	4,06 (0,80)
the development of intersectoral crisis intervention <sup>c</sup>	4,05 (0,97)	3,70 (0,93)
Services activities daily living (ADL) for people with disability accessible to all elderly <sup>c</sup>	3,97 (1,00)	3,74 (0,97)
developing cross-sectoral exchange of functions and personnel <sup>c</sup>	4,26 (0,81)	3,94 (0,91)
aligning regulations between the two sectors	4,27 (0,81)	3,73 (0,93)
coordinating regional consultations	4,03 (0,90)	3,86 (0,94)
providing additional resources	4,59 (0,65)	3,62 (1,05)
personal budgets that can be used in both sectors	3,79 (0,93)	3,41 (0,99)
regulate chronic care within the same administration/ministry <sup>a</sup>	4,15 (0,85)	3,72 (0,93)
new experimental projects, apart from regulation	3,94 (0,92)	3,72 (0,91)
an environmental analysis	4,27 (0,77)	4,01 (0,84)
openness / collaboration between sectors	4,38 (0,69)	4,03 (0,79)
<b>Average</b>	<b>4,16 (0,84)</b>	<b>3,83 (0,91)</b>

Gray = disagreement between sectors

## Notable significant differences between practitioners disability care, regular (elderly) residential care, homecare and users about a **cooperation model**

- More recallable help: users > homecare > regular care > disability care
- Intersectoral crisis aid: users > disability care = homecare > regular care
- Making ADL networks accessible to both sectors: users > disability care = homecare > regular care
- Job Sharing: Users > disability care > homecare > regular care
- Same government: regular (elderly) care = users > disability care

" To support aging persons with disabilities, support within **disability care** is desirable / feasible)



## Joint opinion across groups

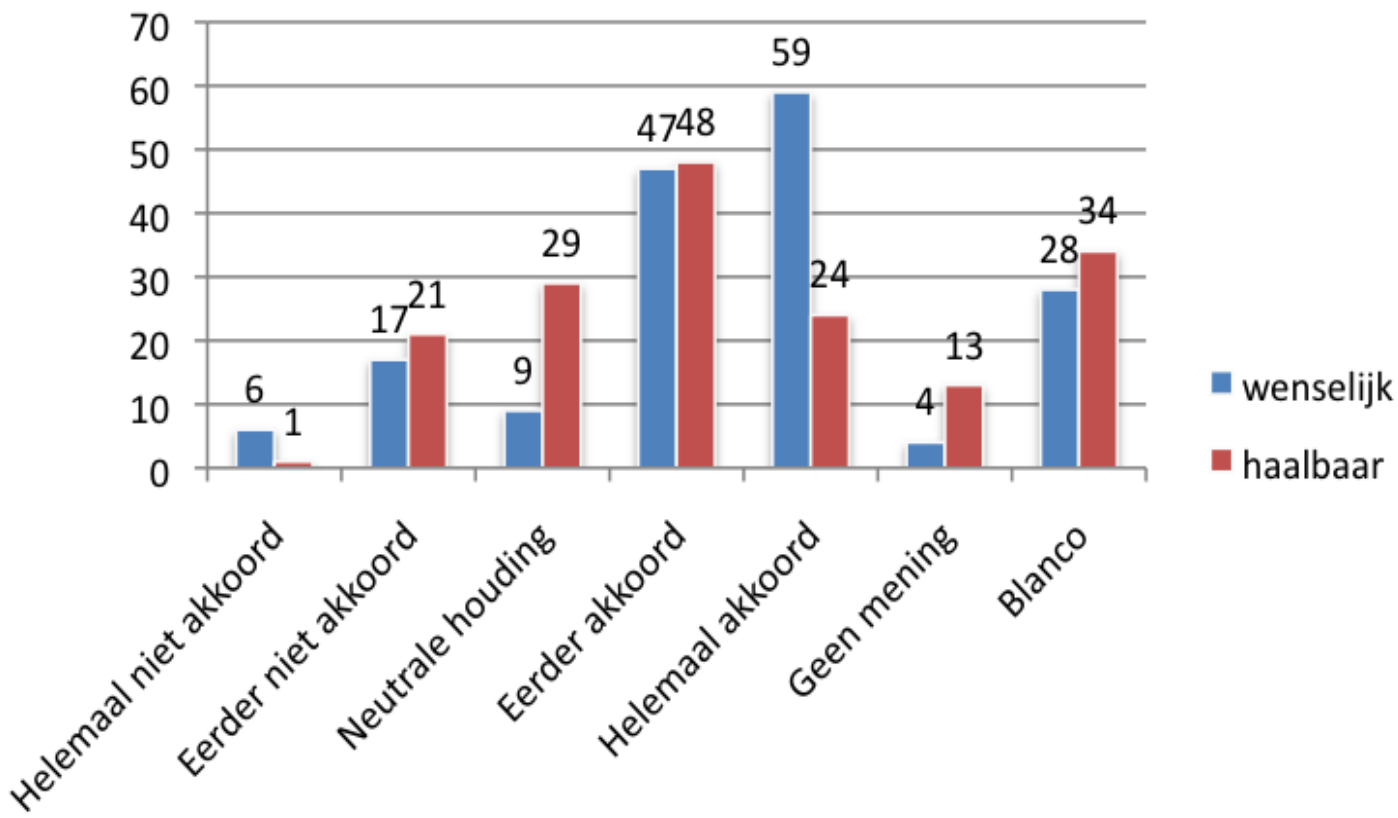
	Desirability M (SD)	Feasibility M (SD)
<b>SUPPORT WITHIN DISABILITY CARE <sup>c</sup></b>	<b>4,50 (0,70)</b>	<b>4,09 (0,85)</b>
investing in nursing and medical care	4,49 (0,73)	3,97 (0,82)
differentiate by making homogeneous age groups <sup>a</sup>	3,74 (1,06)	3,75 (0,87)
building their own expertise in palliative care	4,34 (0,90)	4,11 (0,90)
regular home nursing care in homes for the disabled <sup>c</sup>	4,34 (0,95)	4,05 (0,98)
a new specific type of service for the target group	3,66 (1,11)	3,45 (0,90)
development of expertise on dementia	4,39 (0,78)	4,17 (0,84)
a specific setting for the target audience within the region	3,82 (1,12)	3,61 (0,96)
a less activating approach to elderly <sup>c</sup>	3,49 (1,10)	3,85 (0,89)
equivalent staff salaries across sectors	4,30 (0,85)	3,72 (1,00)
providing additional resources	4,58 (0,58)	3,72 (0,99)
larger scale of care services <sup>a</sup>	3,27 (1,12)	3,19 (1,05)
abolishing the registration age limit (65 years)	3,99 (1,07)	3,71 (1,04)
specific training for staff <sup>a</sup>	4,66 (0,51)	4,39 (0,68)
a more rapid possible change of care service	4,37 (0,79)	3,74 (0,96)
training with nursing and support aspects	4,34 (0,78)	3,95 (0,85)
public support for necessary additional resources	4,47 (0,63)	3,77 (0,84)
the creation of additional support options for the target group	4,57 (0,64)	3,69 (0,92)
<b>Average</b>	<b>4,18 (0,86)</b>	<b>3,83 (0,91)</b>



## Notable significant differences between practitioners disability care, regular (elderly) residential care, homecare and users about a **disability care model**

- Desirability disability services: disability care > users > regular (elderly) care
- Home nursing in residential disability care : disability care > users > regular (elderly) care
- Nursing actions by support worker: disability care > users > regular (elderly) care
- Scaling: homecare > users = disability care
- Training staff: disability care > users > disability care

("To support aging people with a disability, support within the **regular residential elderly care** is desirable / feasible "



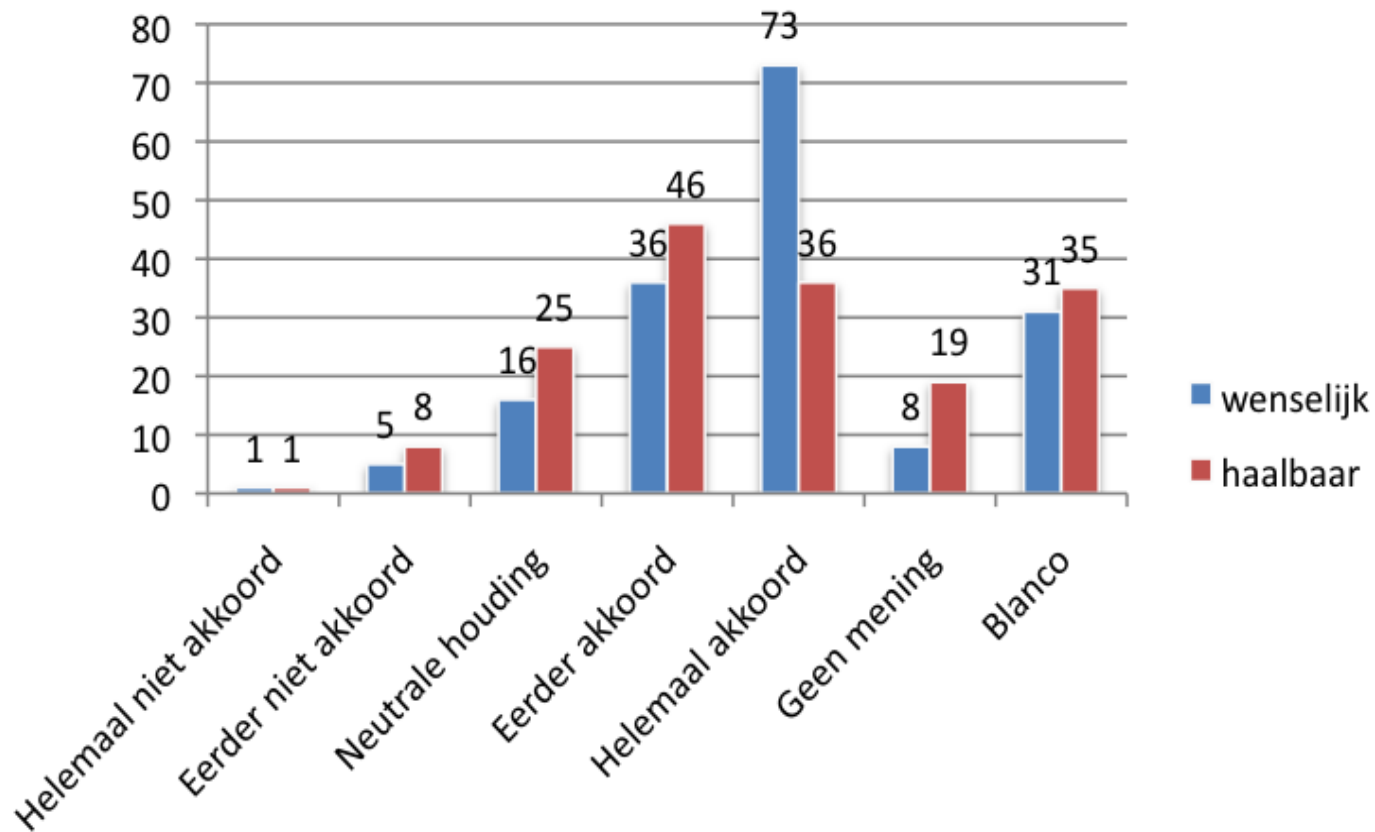
## Joint opinion across groups

	Desirability M (SD)	Feasibility M (SD)
SUPPORT IN Residential elderly Care <sup>a</sup>	3,99 (1,18)	3,59 (1,02)
a more extensive daycare program	4,26 (0,76)	3,72 (0,95)
more appropriate support in addition to providing care	4,49 (0,64)	3,79 (0,95)
develop their own expertise about disability	4,43 (0,71)	4,01 (0,81)
especially within home care services <sup>c</sup>	4,03 (0,87)	3,61 (0,89)
this especially in elderly care services	4,09 (0,86)	3,78 (0,85)
integrated case management	3,96 (0,86)	3,59 (0,85)
Moreagogically qualified staff <sup>a</sup>	4,38 (0,73)	3,82 (0,89)
the creation of additional support options for the target group	4,40 (0,74)	3,73 (0,94)
providing additional resources	4,48 (0,67)	3,69 (0,90)
daily allowance as in residential services for people with a disability	3,99 (0,96)	3,39 (0,78)
equal remuneration for staff across sectors	4,33 (0,84)	3,76 (0,93)
more specific training for staff	4,58 (0,60)	4,18 (0,72)
training with nursing and support aspects	4,43 (0,72)	4,01 (0,79)
abolish the age limit of 65 years for disability services	4,12 (1,00)	3,75 (1,02)
<b>Average</b>	<b>4,26 (0,81)</b>	<b>3,76 (0,89)</b>

## Notable significant differences between practitioners disability care, regular (elderly) residential care, homecare and users about a **residential elderly care model**

- Desirable in residential elderly care: regular (elderly) care > users > disability care
- Better through home care services: home care = users > disability care
- More agogical staff: disability care = regular (elderly) care > users

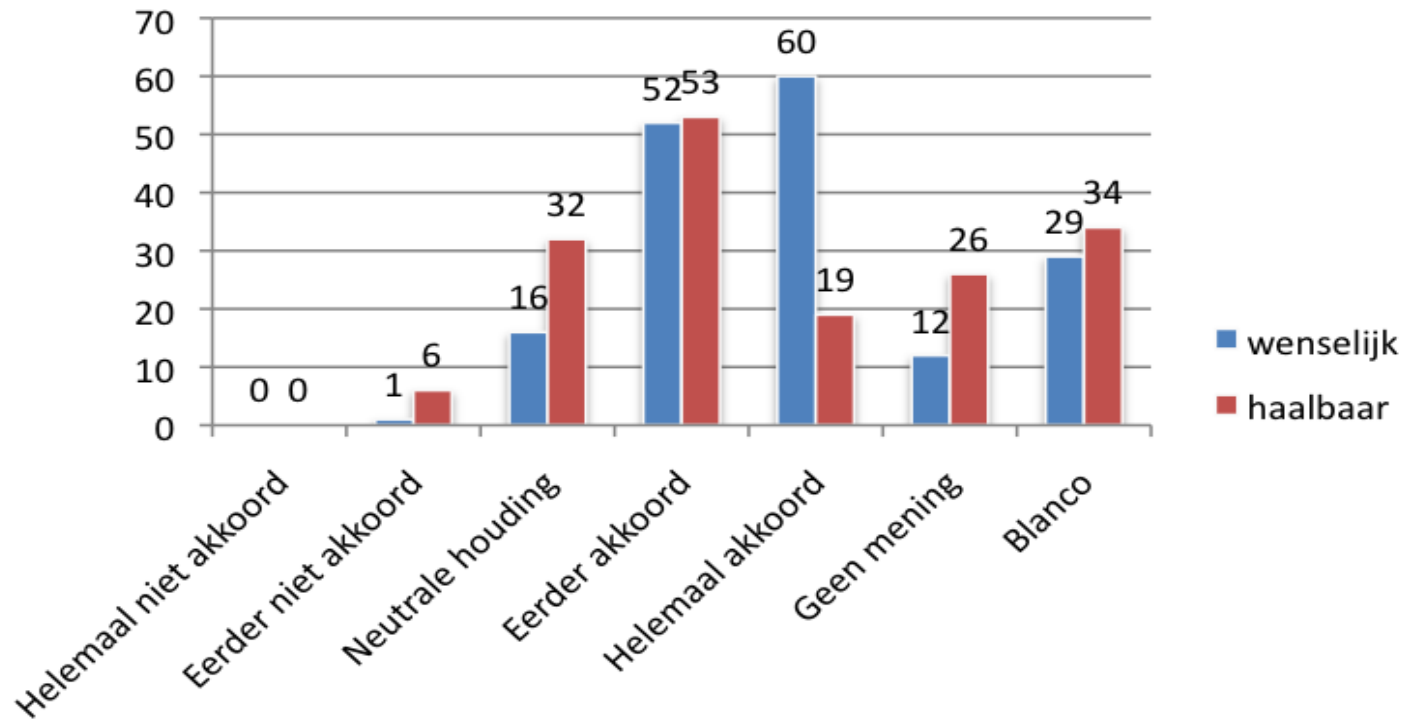
("To support aging individuals with disabilities, more support to **caregiving family members** desirable / feasible ")



## Joint opinion across groups

	Desirability M (SD)	Feasibility M (SD)
<b>SUPPORT FOR CAREGIVING / SELFCARE / FOSTERCARE</b>	4,34 (0,89)	3,93 (0,94)
more forms of recallable support/assistance	4,43 (0,73)	4,11 (0,79)
ensuring aid during crisis situations	4,53 (0,68)	3,70 (0,90)
simplifying administration	4,53 (0,65)	4,11 (0,79)
establishing information centres	4,24 (0,88)	4,00 (0,84)
making the home environment accessible	4,55 (0,66)	3,92 (0,84)
expanding service vouchers to care vouchers	4,26 (0,95)	3,71 (0,97)
helping to develop social networks	4,45 (0,67)	3,82 (0,84)
invest in voluntary work within home care	4,34 (0,79)	3,83 (0,95)
reducing waiting times in both sectors	4,63 (0,57)	3,32 (1,05)
ensuring sustainability of intensive home care	4,60 (0,63)	3,47 (0,94)
an environmental analysis	4,33 (0,77)	3,95 (0,78)
systematically follow up (older) carers	4,26 (0,78)	3,60 (0,91)
smooth transition from outpatient to residential care	4,65 (0,59)	3,63 (0,98)
expansion of support option in foster care / guest host	4,11 (0,90)	3,41 (0,93)
extending adapted and accessible housing	4,52 (0,71)	3,78 (0,92)
<b>Average</b>	<b>4,42 (0,74)</b>	<b>3,77 (0,90)</b>

To support aging persons with disabilities, **a revision of the way financial resources are granted** is desirable / feasible



## Joint opinion across groups

	Desirability M (SD)	Feasibility M (SD)
CRITERIA FOR THE REVISION OF GRANTED FUNDS	4,33 (0,72)	3,77 (0,80)
what the person asks	3,83 (1,08)	3,10 (1,11)
an age limit <sup>a</sup>	2,42 (1,17)	2,91 (1,19)
diagnosis	3,87 (1,04)	3,80 (0,97)
degree of functional disability	4,45 (0,74)	4,15 (0,81)
a unifying classification elderly/disabled to assess the need for care	4,30 (0,88)	3,95 (0,97)
assessing family financial standing	3,34 (1,35)	3,23 (1,22)
assessing caring family standing	3,97 (1,09)	3,56 (1,09)
assessing the income of the person	3,80 (1,18)	3,66 (1,12)
<b>Average</b>	<b>3,81 (1,03)</b>	<b>3,57 (1,03)</b>



# A matter of disability?

## REGULAR CARE SERVICES

	Desirability M (SD)	Feasibility M (SD)
mild mental retardation: existing residential (elderly) care	3,43 (1,14)	3,49 (0,99)
mild mental retardation: adapted residential (elderly) care	3,83 (1,09)	3,78 (1,02)
moderate mental retardation: existing residential (elderly) care <sup>a</sup>	2,78 (1,31)	2,95 (1,15)
moderate mental retardation: adapted residential (elderly) care	3,24 (1,31)	3,25 (1,21)
severely mentally retarded: existing residential (elderly) care	2,35 (1,22)	2,43 (1,13)
severe mental retardation: adapted residential (elderly) care	2,68 (1,35)	2,66 (1,24)
Non-congenital brain damage: existing residential (elderly) care	2,82 (1,19)	2,83 (1,12)
Non-congenital brain damage: adapted residential care	3,38 (1,22)	3,25 (1,16)
disability and dementia: existing residential (elderly) care <sup>a</sup>	3,34 (1,22)	3,27 (1,10)
disability and dementia: adapted residential (elderly) care	3,75 (1,17)	3,59 (1,15)
early dementia: existing residential (elderly) care	2,95 (1,30)	2,91 (1,12)
early of dementia: adapted residential (elderly) care	3,33 (1,35)	3,25 (1,22)
mild mental retardation: existing residential (elderly) care	3,35 (1,24)	3,55 (1,10)
physical disability: adapted residential (elderly) care	3,70 (1,23)	3,81 (1,08)
visual impairment: existing residential (elderly) care	3,42 (1,19)	3,49 (1,06)
visual impairment: adapted residential (elderly) care	3,82 (1,14)	3,75 (1,08)
hearing impairment: existing residential (elderly) care	3,42 (1,21)	3,50 (1,07)
hearing impairment: adapted residential (elderly) care	3,79 (1,15)	3,71 (1,07)
Autism: existing residential care <sup>b</sup>	2,25 (1,14)	2,11 (1,01)
Autism: adapted residential care	2,59 (1,30)	2,34 (1,15)
behavioral problems: existing residential care <sup>c</sup>	2,19 (1,09)	2,18 (0,99)
behavioral problems: adapted residential care	2,50 (1,28)	2,41 (1,18)
psychological problems: existing residential care <sup>a</sup>	2,43 (1,16)	2,34 (0,97)
psychological problems: adapted residential care	2,82 (1,30)	2,63 (1,12)
<b>Average</b>	<b>3,09 (1,22)</b>	<b>3,06 (1,10)</b>

## DISABILITY CARE SERVICES

	Desirability M (SD)	Feasibility M (SD)
mild mental retardation: current disability care services	3,61 (1,03)	3,67 (0,98)
mild mental retardation: adapted disability care services	3,87 (1,04)	3,92 (0,96)
moderate mental retardation: current disability care services	3,87 (0,90)	3,76 (1,02)
moderate mental retardation: adapted disability care services	4,20 (0,85)	4,04 (0,93)
severely mentally retarded: existing disability care services	4,07 (1,00)	3,68 (1,11)
severe mental retardation: adapted disability care services	4,31 (0,85)	4,00 (0,99)
Non-congenital brain damage: existing disability care services	3,59 (1,01)	3,37 (1,03)
Non-congenital brain damage: adapted residential (elderly) care	4,03 (0,98)	3,71 (0,98)
disability and dementia: existing residential disability services	3,39 (1,22)	3,19 (1,13)
disability and dementia: adapted residential disability care	3,77 (1,17)	3,52 (1,09)
early dementia: existing residential disability services	3,45 (1,16)	3,11 (1,10)
early of dementia: adapted residential disability services	3,83 (1,15)	3,46 (1,07)
physical impairment: existing residential disability care services	3,62 (1,08)	3,68 (0,97)
physical impairment: adapted disability care services	3,86 (1,07)	3,97 (0,92)
visual impairment: existing disability services	3,50 (1,10)	3,52 (0,99)
visual impairment: adapted disability services	3,69 (1,11)	3,82 (0,98)
hearing impairment: existing disability services	3,48 (1,11)	3,53 (0,98)
hearing impairment: adapted disability care services	3,70 (1,12)	3,82 (0,95)
autism: existing disability care services	3,93 (0,94)	3,50 (1,02)
autism: adapted disability care services	4,21 (0,85)	3,88 (0,97)
behavioral problems: existing disability care services	3,81 (0,97)	3,22 (1,08)
behavioral problems: adapted disability care services	4,17 (0,89)	3,74 (1,03)
psychological problems: existing disability services	3,66 (1,02)	3,12 (1,07)
psychological problems: adapted disability services <sup>c</sup>	4,04 (0,98)	3,65 (1,04)
<b>Average</b>	<b>3,82 (1,03)</b>	<b>3,62 (1,02)</b>

## Notable significant differences between practitioners disability care, regular (elderly) residential care, homecare and users about **target groups**

- disability sector finds herself *significantly* more suitable to support:
  - Mild mental handicap
  - Moderate intellectual disability
  - Severe mental retardation
  - Dementia and early dementia
  - Physical disability
- Regular care sector finds itself more suited to support:
  - Mild intellectual disability
  - Moderate intellectual disability
  - Severe intellectual disability



# Policy issues

# Priorities in the field

Policy Option	Priority
Support cooperation between care sectors	90
More resources	68
Expertise of staff	57
Reduce waiting lists	25
Revision of Age limit	22
New specific forms of support for disabled elderly	15
New Criteria to allocate resources	13

# Recommendations for policy

- Strengthening the people themselves and informal caregiving
  - Stimulation of intersectoral information provision and clarification of user demands
  - Fostering intersectoral case consultations, care planning and -mediation
  - Strengthening of accessible and specialized outpatient care
  - Simplify administration applications
- Care guarantee, provided certain conditions
- Encouraging intersectoral entrepreneurship
  - Accessibility and adjustments based on profiling
  - Outreaching to help other professionals to specialize
  - Structural cooperation on housing, daily activities and leisure
  - Seizing the opportunities of new legislation (outpatient care zones)

# (Bigby, 2002)

- Several strands of policy and service development are needed to effectively meet the needs of older people with lifelong disability. These can be broadly categorised as:
  - systematically **bridging gaps with specialist services**, where neither sector has appropriate services to meet needs;
  - supporting inclusion and ensuring that older people with lifelong disability are **visible within the aged care system**;
  - adapting and resourcing disability services to facilitate **ageing in place**;
  - and developing partnerships and joint planning aimed at the removal of cross- and intra-sector obstacles

Bigby, C. (2002). Ageing people with a lifelong disability: challenges for the aged care and disability sectors. *Journal of Intellectual & Developmental Disability*, 27 (4), 231–241.