Intellectual Disabilities (ID) and ageing/dementia:

State of the art, questionnaires and qualified assessment

Joop Hoekman & Marian Maaskant

Uppsala, november 23th, 2010

Zonnehuizen

Universiteit Leiden

stichting pergamijn kleurt je leven!

GKC

Maastricht University Leading in Learning!

Ageing and dementia in persons with ID

Is it really an important topic?

About ‘the building of human spirit in mentally deficients’:

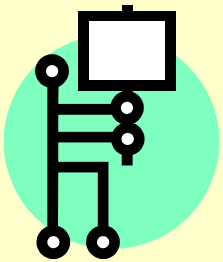
‘Usually, it is not one main function that lacks, there are more. Although the mysterious spirit of life still tries to construct the building, the final result definitely is poor.
The construction progresses slower and slower. Finally, it ends premature’

Citation from 1972

(Van der Most G, Fennis JPM, Diepen R., 1972, p.13)

Citation from 2009

Congresses of persons with ID: declarations



We want to decide ourselves what we do.

We are human being, our disabilities are side issues.

We never ever will proceed to the order of the day again.

Outline

Marian Maaskant

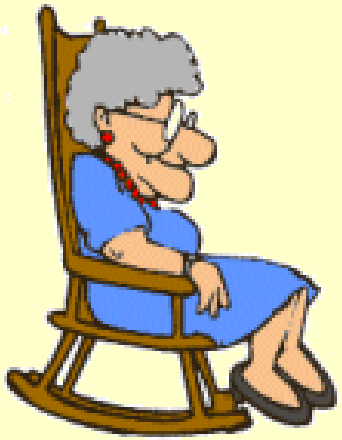
- Ageing
  - Life expectancy
  - Number of elderly with ID
  - Infirmities
  - Support
- Dementia
  - Results literature review

Joop Hoekman

- Dementia scales
- DMR & DSDS
- DSVH
  - Motivation
  - Psychometric qualities
  - Using DSVH
- Conclusions

Ageing

- Life expectancy
- Number of elderly with ID
- Infirmities
- Support



Life expectancy

- Persons without ID:
  - Sweden, NL: ± 81 years
  - Oezbekistan: ± 68 years
  - Zimbabwe: ± 44 years

- Persons with ID (W-Europe, USA):
  - 1929: 6 years
  - 1948: 12 years
  - 1961: 18 years
  - 2008: 50 years (mild ID, normal LE)

Ageing: numbers

50+ with ID in NL:

2002:	15% (16.000)
2020:	25% (26.000)

(SCP, 2005)

50+ with ID in residential settings:

	50+	65+
1984:	15%	5%
1996:	24%	8%
2011:	39%	11%

(Bernard e.a., 2001)

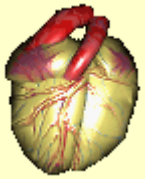
Infirmities

Infirmities (age limits)

- General population:
  - 65 years (usually retiring age)

international limits

- ID:
  - 50 years
- Down syndrome and severe/profound ID:
  - 40 years



Infirmities (age 50+)

- Visual handicaps (>25%)
- Auditive handicaps (>50%)
- Cardiac problems (>20%)
- Infirmities of gastrointestinal tract (>10%)
- Infirmities of urogenital tract (>5%)
- Dementia (>10%; DS: >50%)
- Musculoskeletal problems (>20%)

- Decrease daily living skills
- Decrease mobility

Nothing special (excl. dementia), but at younger age and more prevalent

Haveman M et al. Health Risks in Aging Persons With Intellectual Disabilities: An Overview of Recent Studies. **JPPID 2010, 7, 1, 59-69**

Infirmities (additional info)

- Many infirmities never diagnosed
- Many infirmities life-long present
- Syndrome-specific infirmities
- Dementia
  - Also in persons with ID
  - Down syndrome (and some rare syndromes): increased risk
  - Diagnosis is difficult due to ID
    - several tests and rating scales (e.g., DSDS, CAMDEX-D, MOSES)

Support

Support

Present vision on ID

- Quality of life
- Citizenship
- Community care
- Respect, individualism
- Autonomy
- Support as requested, to decrease the disadvantages of the disabilities

Support of elderly

Adapted support:

Changes:

- Physically (e.g., sense, mobility)
- Psychological (e.g., depression, loss of work)
- Socially (e.g., decrease social network)
- Spiritually (e.g., one's finiteness)
  - Meeusen R, et al. Death and management of grief in people with intellectual disability. **JPPID 2006, 3, 2, 95-104.**

– Focus not anymore on development
– Focus on maintenance of skills / decrease as minimal as possible

Dementia: Literature review

Strydom A, Dementia in Older Adults With Intellectual Disabilities - Epidemiology, Presentation, and Diagnosis. **JPPID 2010, 7, 2, 96-100**

Literature review

Prevalence

Prevalence of dementia:

General population

- 65+: 6%
- 85+: 25%

Down syndrome

- 40-49 y: 5-20%
- 50-59 y: 20-40%
- 60+: 25-80%

ID general

- 40-49 y: 0-5%
- 50-59 y: 0-5%
- 60+: 5-20%

Literature review

Symptoms of dementia in ID

Many differences between studies:

- Loss of:
  - Interests
  - Motivation
  - (Social) skills
  - Memory
- Self-injurious behaviour
- Brain atrophy on MRI
- Epilepsy (Down syndrome)
- Changes of behaviour

Literature review

Differential diagnoses

- Several diseases show symptoms that resemble dementia
  (e.g., intoxications, delirium, depression, sense impairments)
- These diseases can (partly) be cured

Literature review

Support

- Co-residents
  - Problems with odd behaviour of co-resident
  - Focus groups to increase sympathy
- Professionals
  - Chance of emotional exhaustion
  - Problems with odd behaviour due to dementia
  - Some knowledge of dementia
  - Focus groups to increase knowledge
  - Contact between companions (fellow-sufferers)
- Family
  - Hardly plans
  - Contact between companions (fellow-sufferers)

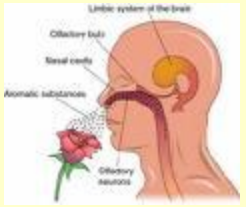
Literature review

Education

- Education necessary
  - Characteristics dementia
  - Differential diagnoses
  - Recognizing pain, fear
  - Coping problem behaviour
  - (Medical) decisions, palliative care
    (Thesis Tuffrey, in English)
  - Mourning, coping with loss

Possible interventions dementia

- Reminiscence
- Warm care
- Validation
- Cognitive therapy, stimulation
- Aroma therapy
- Music therapy
- Movement therapy
- Pharmacological means



Literature review

Interventions dementia

- Many interventions did not show effects yet
- Many interventions hardly tested on persons with ID
- Studies: often case-studies, small groups, qualitative research
- Dependent of stages of dementia and level of ID

Ageing and dementia in persons with ID

- Is it really an important topic?

YES!!!!!!

Dementia

Markant (NL journal), special issue on dementia; november 2009

Support staff Jeanette Derks:

‘You know that people that come to live here are going to worsen at a certain time and are going to die. What stimulates me and my collegues the most in working with these clients is: taking care that they can live the last stage of their life with dignity.’

Mr. Larsson

- 64 years old
- Lives with professional support
- Confuses names
- Often sad
- Problems with finding his room
- Buttons his shirt
- Puts his coat on before breakfast

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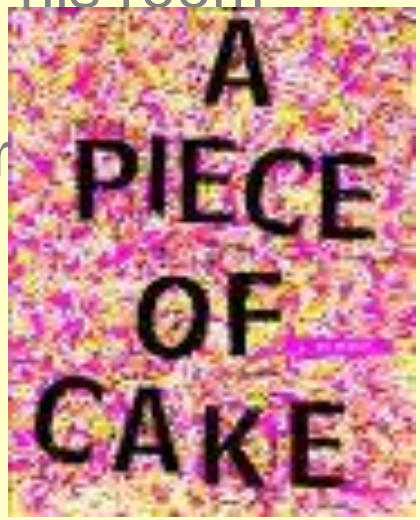

➔ dementia!

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~~➔ dementia!~~

Dementia scales for persons with ID

Several tools are available:

- Screening / rating tools completed by or with caregivers
  (e.g., DMR, CLD, DSDS, CAMDEX, MOSES)

- Screening tools based on individual performance
  (e.g., MMSE, TSI, DMTS, Brief Praxis test)

- (neuroimaging, EEG)

Most of them in English, and thus not easily applicable in Nordic Coutries / the Netherlands






Dementia scales: which one to use?

- Study on comparison of usefulness of 3 scales
  (Hoekman, J & Maaskant, M.A. (2002). Comparison of instruments for the diagnosis of dementia in individuals with intellectual disability, *JIDD, 27, 4*, 296-309)
- Classification dementia ⇔ no dementia
  - experts (physician / psychologist), using ICD 10 or DSM IV

  versus

  - results of scales

Study on dementia scales

- Research 1999/2002
  - DMR (Dementia rating scale for Mental Retardation; Evenhuis)
  - CLD (Checklist early symptoms of dementia in ID; Visser)
  - DMTS (Delayed Match-To-Sample test; Dalton & McMurray)

- Agreement with expert opinion low:
  - DMR kappa 0.26
  - CLD kappa 0.35
  - DMTS kappa 0.25

  (kappa has to be 0.6 at least)

- Mutual agreement low: kappa <0.30

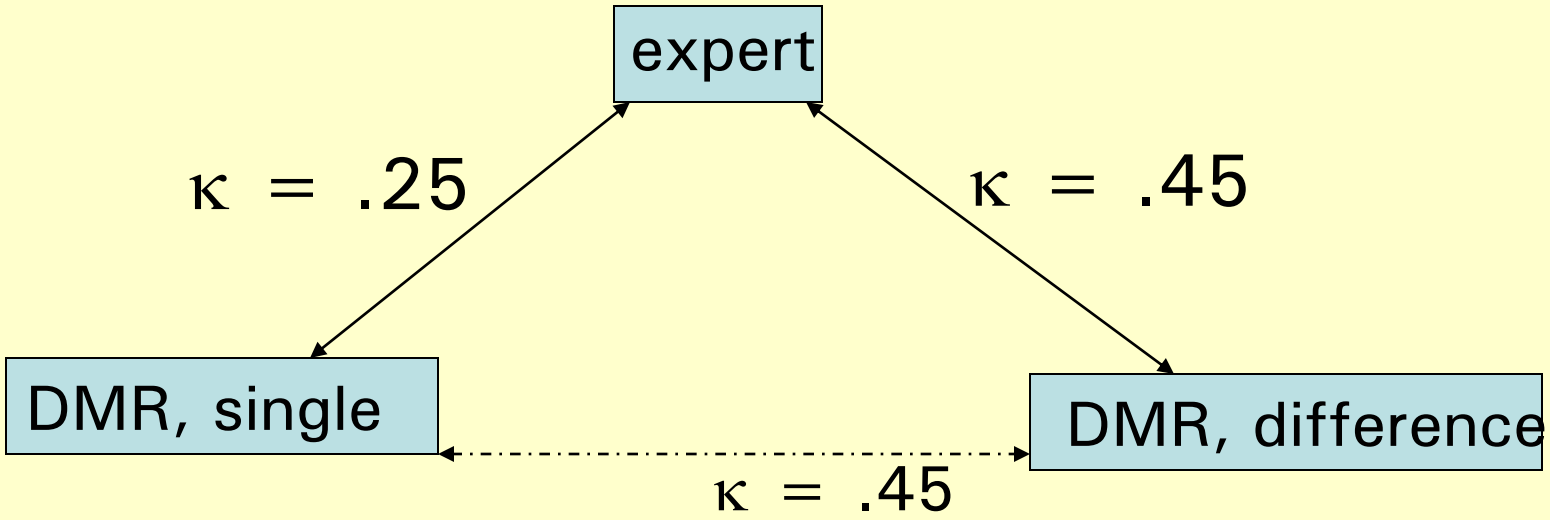
- **Doubts about their usefulness**

DMR & DSDS

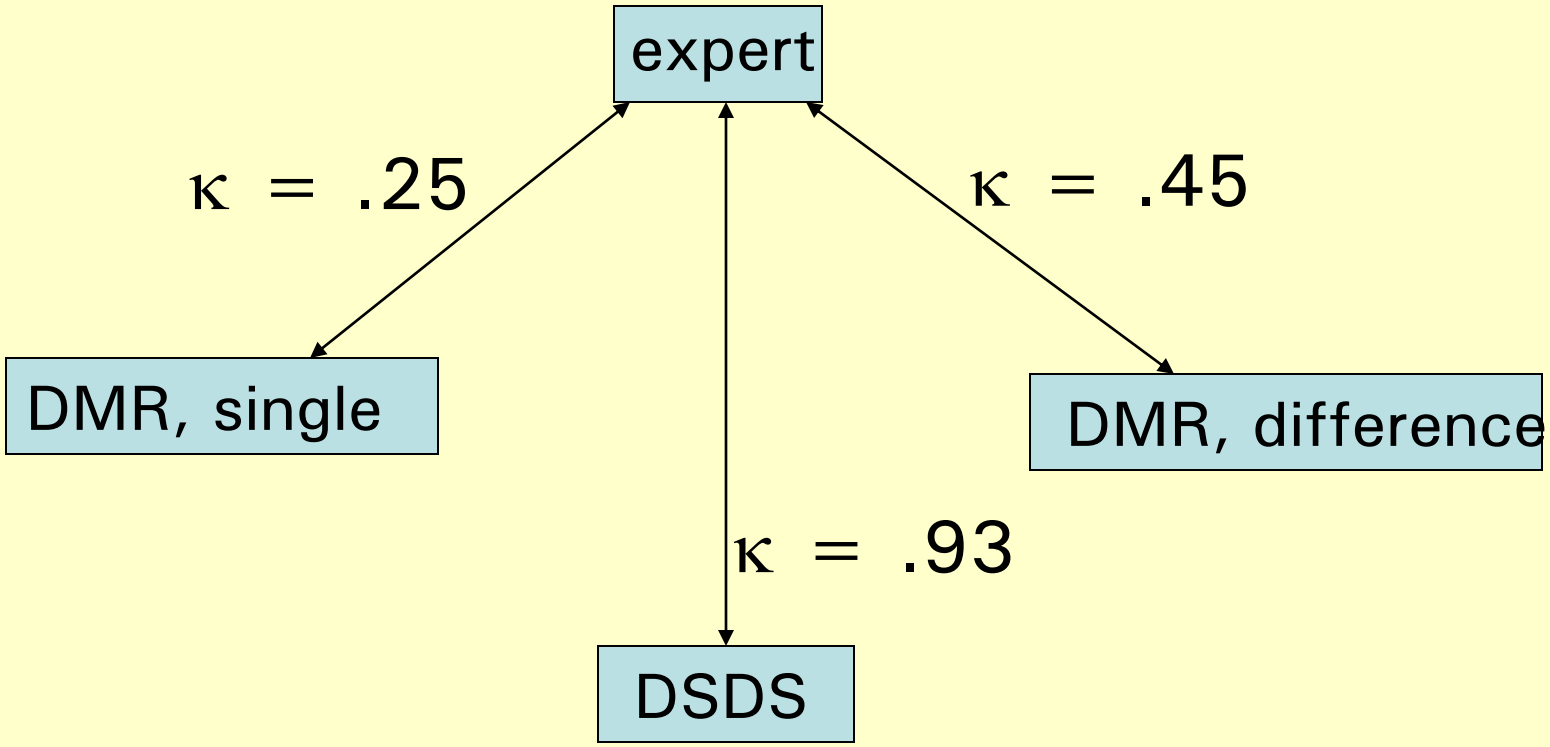
- DMR: Dementia questionnaire for Mentally Retarded persons (Evenhuis et al.)
- Old norms for single measurement (1991-1996)
- Norms for difference scores between two measurements (1998)
- N = 41

- DSDS: Dementia Scale for Down Syndrome (A. Gedye, Canada)

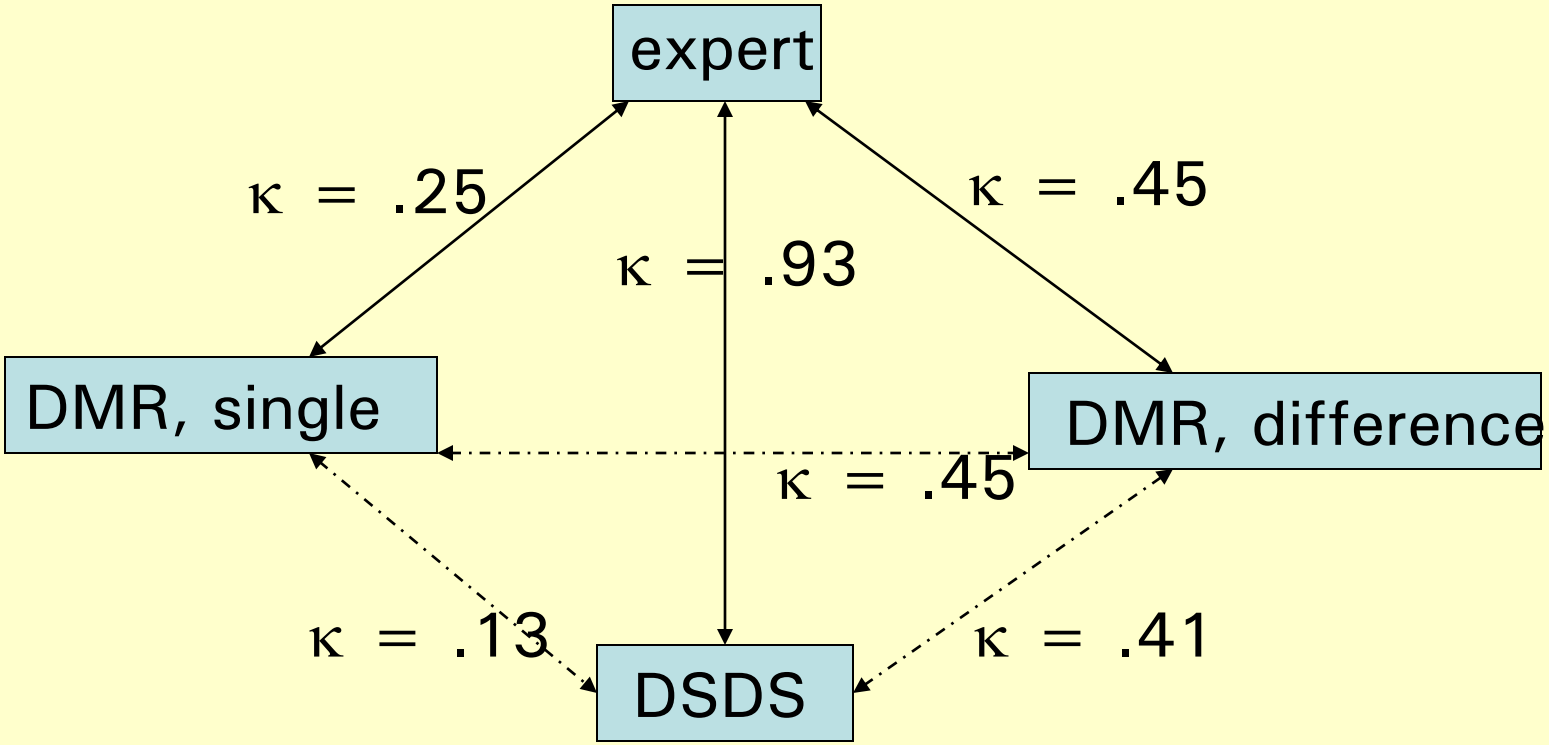
DMR



DMR compared with DSDS



DMR compared with DSDS



DMR compared with DSDS: conclusion

Agreement expert – DMR: too low

Agreement expert – DSDS: (very) good

Mr. Salander

- Moderate ID
- Hobby: trees and plants
- Works at garden centre of service providor
- Not talkative
- Moderate daily living skills

Mr. Salander

60 years:

- Forgetful

64 years:

- Loss of daily living skills and memory
- Hardly any interest in hobby, sad
- Fearful
- No other explanations for changes (differential-diagnoses)

Mr. Salander

64 years (contn.)

- Diagnosis dementia
- Adapted support
  - Support when needed
  - Less fearful

- 65-67 years
  - Increasing dependency on care, bedridden

- 67 years: deceased

Usefulness of the DSVH dementia scale for persons with ID

New test?

- DSDS; *Dementia Scale for Down Syndrome*; dr. Angela Gedye (Can.)
- Seemed useful (agreement with experts satisfactory)
- Translation in Dutch

DSVH

- Items and differential diagnoses questions adapted from the DSDS
- Behavior rating scale (client participation preferred, not required)

Compared to DSDS:

- Slightly different order of items
- New handbook
- New norms

How does DSVH work?

- Interview of psychologist (qualified and trained in testing) with
  - informants (family, staff) who know person involved well
  - client (when possible)

- First interview: 1 hour; next interview usually shorter

How does DSVH work?

- Informs about present and relevant functioning, relative to pre-morbid functioning
- Differs between *typical* (characteristic), *present* and *n/a* functioning
  - Typical: urinary incontinence (was always the case)
  - Present: now forgets names of common objects (was not the case in the past)
  - N/A: never could read and write
- Helps to exclude conditions that mimic dementia (Cases Mr. Svensson, Ms. Blomkvist)

Ms. Blomkvist

- 39 years old, Down syndrome
- Lively, sociable
- Hobby: painting
- Healthy, with
  - decompensated heart (digoxine)
  - *some visual and hearing impairments (glasses, no hearing aid)*

Ms. Blomkvist

- ‘Suddenly’:
  - Messing up with painting
  - Apathetic
  - Decrease of daily living skills

- Dementia??
- DSVH with differential-diagnosis

- Intoxication by Digoxin!!
- Other medication and then…..

Ms. Blomkvist

It was all–right again

How does DSVH work?

60 items about functioning

Examples:

1. Forgets partway through familiar routines what s/he is doing (eating, toileting, setting table)
11. Uncharacteristic irritability, more easily upset
26. Speaks of remote events as if they were current
29. Initiates speech less often; fewer communicative gestures if person has no speech
42. No longer recognizes closest friends/relatives or is forgetting their names

How does DSVH work?

- 60 items
  - #1-20 stage 1
  - #21-40 stage 2
  - #41-55 stage 3
  - #56-60 stage 4
- Results
  - classification dementia present – absent
  - indications of stage of dementia

Psychometric qualities of DSVH

Study group:

- n=407
  - Mean age 56
  - 63% Down syndrome
  - Mild ID 15%, mod. ID 59%, sev/prf. ID 26%
- From several service providers in NL
- Diagnoses dementia yes-no:
  - Expert opinion (psychologist and physician, based on DSM-IV-TR and/or ICD-10 criteria
  - DSVH
- Validity study: split in n=203 and n=204

Results interrater reliability

Expert opinion	DSVH		total
	no	yes	
no	120	11	131
yes	3	70	73
total	123	81	204

Kappa: 0.85 (95% CI: 0.78-0.93); sensitivity 96%; specificity 92%

Results validity

- Criterion validity (cross-validity); n=203
  - kappa: 0.88 (95% CI: 0.82-0.95)
  - sensitivity 94%
  - specificity 95%
- Convergent validity
  - kappa with DMR is –of course- low: 0.5
  - no alternatives available

Results interrater reliability

Informant 2 Informant 1	no dementia	dementia	total
no dementia	6	1	7
dementia	1	22	23
total	7	23	30

Kappa: 0.81 (95% BI: 0.57-1.00); sensitivity 96%; specificity 86%

Results stages

Stages of dementia

- several authors use different numbers of stages

- no criteria for stages available
- persons may switch between stages

➔ only qualitative indications

Conclusion DSVH

DSVH is

- sufficiently reliable and valid
- a valuable diagnostic instrument

Conclusion DSVH

However!

- DSVH is only a tool
- Never use the outcome as the only diagnostic criterion
- It always has to be part of an extensive diagnostic process

- After the diagnosis, the real work starts: Respectful and methodic support of persons with dementia!

Conclusions general

- Ageing is an increasing issue in ID
- Ageing is a ordinary stage in life, with advantages and disadvantages
- The present vision on ID is valid for seniors, but!
  - support needs to be adapted to their needs and wishes
  - support is different than in their younger years

Conclusions general

- Dementia is an increasing issue in ID
- Properly diagnosing dementia is essential for adequate support
- After the diagnosis:
  - Respectful and methodic support is needed
  - Just as for those who do not develop dementia

But ageing is relative….

Interview with Jane, 72 years, woman with ID:

Ageing…

Jane:

Ik am 72. I still feel young, here (points at her head). I am young when thinking. Being 80 years, thát's old!

(Urlings e.a., 1995, p.118)

for your attention!

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stichting pergamijn kleurt je leven!

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