

#### Challenges: social functioning

- Direct effects of visual disability
  - immitation communication
  - mobility energy
  - appearance
- Indirect effects of visual disability
  - social support social contacts
  - stigmatisation dependency
  - · confidence/self-esteem



## Scientific results and clinical experiences

- Mixed scientificresults: considerations →
- Clinicalorcommunitybased samples
- Country
- Which decade/period
- Methodological design
- Social functioning seems at risk: but not for everyone with a visual disability! What are the riskfactors, or in a more positive way: what predicts 'good social functioning'?



Theoretical framework Social support Characteristics Network visual disability Psychological Well-being -degree characteristics -course Loneliness competence -heredity Parenting styles of parents VU University Amsterdam

# Research question

1. What are important factors for social functioning of young persons with visual disabilities?

A national longitudinal scientific project with two large cohorts of young persons with visual disabilities living in the Netherlands.

The participants form a mixed clinical- and community based sample.

Results presented at this conferene are based on several smaller projects within the national study (more information: see the websites on the last slide).



# **Participants**

1996	2004/2005	2010	
Sample 1 14-24 years old N= 316	Sample 1 22-32 years old N=205	Sample 1 28-38 years old N=179	
-	Sample 2 14-21 years old N= 154	Sample 2 20-27 years old N=112	
Psychosocial functioning, coping, social network	Psychosocial functioning, social network, personality	Psychosocial functioning, social network, (transition to) parenting	



#### Demographics sample 1: young adults wave 2

56% male 44% partially sighted 78% female 38% progressive partner yes 58% stable 62% living situation: work/school situation: independently 64% school/study 52% 23% parents 34% study and job institution 3% job 15% unemployed 10% club member/ 77% regular trajectory 45% leisure special education 55%



#### Demographics sample 2: adolescentswave 1

20% male 54% blind female 46% partially sighted 80% progressive 35% partner yes 41% stable 65% work/school situation: living situation: independently 5% school/study 56% 82% study and job 39% parents institution 13% job 2% 3% unemployed club member/ regular trajectory 48% 80% special education 52% leisure



# Participants (2)

- · 160 parents of adolescents in 2005
- · 10 siblings of adolescents in 2005
- · 10 best friends of adolescents in 2005
- 40 itinerant teachers of adolescents in 2005
- 96 romantic partners of young adults in 2010
- · 35 professionals working in rehabilitation in 2010
- · 92 young persons without visual disabilities in 2010



#### Method

- 1. Computer Assisted Personal Interviews in their homes
- 2. Telephone interviews (CATI)
- 3. Online questionnaires
- 4. Paper and pencil questionnaires
- 5. Personal interviews at school

Interviews and questionnaires are composed of standardized reliable questionnaires and qualitative open-end questions. Some compensating strategies in datacollection were nescessary because of the visual disability.



#### Results - Social networks

- Size: smaller. Small difference. Could be logical because of mobility. Could be a risk in case of changing schools, sickness etc.
- 2. Satisfaction with size: quite high, but wish for more contacts with sighted peers
- 3. Composition: more older friends. Positive and negative aspects of this finding
- 4. Smaller number of friends but quite high quality of friendships
- 5. Satisfaction with social support
- 6. Worries and doubts with regard to dating, courtship, sexuality. Less experiences and at an older age.



# Results – Social competence all social competence scores of young adults with visual disabilities are significantly lower than youth without disabilities. 4 3,6 3,2 2,8 2,4 2 Soc. acceptance friendship romance VI: young adults VI: adolescents sighted ado.

# Results - Social competence

	Young adults low vision T2 Sample 1	Young adults low vision T3 Sample 1	Adolescents low vision T1 Sample 2	Young adults low vision T2 Sample 2
Social acceptation	2.90	2.78	2.85	2.76
Romance	2.49	3.10	2.29	3.11

Feeling of competence in social acceptation is getting lower Feeling of competence in romance is getting higher Degree of Peer activity: lower compared with sighted peers



## **Results - Loneliness**

	Sample 1 Adolescents T1	Sample 1 Young adults T2	significant
Emotional loneliness	1.33	1.36	p=.82
Social Ioneliness	1.34	0.98	p=.01
Total score loneliness	2.67	2.34	p=.09  Total score > 3 = clinical

Strongest predictor of high loneliness on T2 is high loneliness on T1

Participants without school or work: lowest loneliness score

Disability characteristics and network characteristics: no predictors of loneliness



## Results - Self-esteem and well-being

	Adolescents Low vision T1 Sample 1	Young adults low vision T2 Sample 1	Young adults low vision T3 Sample 1	Adolescents low vision T1 Sample 2	Young adults low vision T2 Sample 2
Self-esteem	3.32	3.43	3.41	3.27	3.48
Well-being	7.9	7.8	7.7	7.8	7.6

Feeling of self-esteem is getting higher/more positive
Feeling of well-being is getting lower
No large differences compared with sighted peers



# Results — Correlations between social functioning and psychological variables

- Some small correlations between social competence, self-esteem, well-being, acceptance of the disabilty, loneliness and size of social network
- Conclusion: there is a relationship between these concepts, however there is quite a large variation within the group.
- The role of objective disability characteristics like degree or course of the disability is small: we found very few differences with regard to social functioning and psychological variables



# Results — Parenting styles of parents of our adolescents in 2004/2005

- Comparable sensitive responsive style as other parents
- Comparablel evels of parenting stress
- Higher levels of stimulating autonomy
- Fathers more overprotective than mothers
- Slightly lower well-being of parents
- Comparable quality of partner-relationship
- Quality partner-relationship important predictor of parenting styles



# Results - Important factors for social functioning of young persons with low vision

- 1. Disability characteristics explain only a very small part of the variance within the group.
- 2. Stronger relations are found between psychological variabels and social functioning, but it is still a small part of the explained variance
- 3. A few relations between parenting styles and social functioning were also found, as are with sighted adolescents on the same topic.
- 4. More differences are found for the domain of social functioning than for the psychological variables in the comparison with sighted peers.
  - → Could this be caused by the direct or indirect low vision effects?
  - → Could this be caused by the attitude, choices and behavior of other persons? While social functioning is impossible without the presence of other persons.



## Conclusion

- Start early in life with stimulating compensating strategies for the 'negative' direct and indirect effects of low vision that are essential for social functioning
- Direct effects of visual disability
  - immitation: tell the child about social behavior that hecannot see himself
  - communication: give information about the existence and meaning of verbal and non-verbal communication
  - mobility: try to train the mobility skills as much as possible
  - energy: explain the child how to use his energy, how to plan his activities
  - appearance: please pay attention to the looks of the child, because other persons judgement and social behavior in Western societies are influenced by it, especially in adolescence



#### Conclusion

- Look further:
  - the total child/person is important
    - Improving social competences/skills and at the same time ignoring mobility, appearance or feelings of self-worth makes no sense
  - the parents and family situation are important
    - Improving social competences/skills of the adolescent and at the same time ignoring overprotection of parents or negative remarks of siblings makes no sense
  - the friends/classmates are important
    - Improving social competences/skills of the adolescent and at the same time ignoring bullying of classmates or misconceptions regarding the disability makes no sense
- Maybe a change in the organization of the support/rehabilitation is needed to really meet the above mentioned conclusions!



# Thank you

- This project was not possible without the cooperation of our participants, whom we want to thank for their honest and inspiring talks about their lives.
- Furthermore we thank our interviewers and we are grateful for the received grants from ZonMw InZicht.

Questions:S.Kef@psy.vu.nl
Website www.psy.vu.nl/verderkijken
www.sabinakef.nl

21