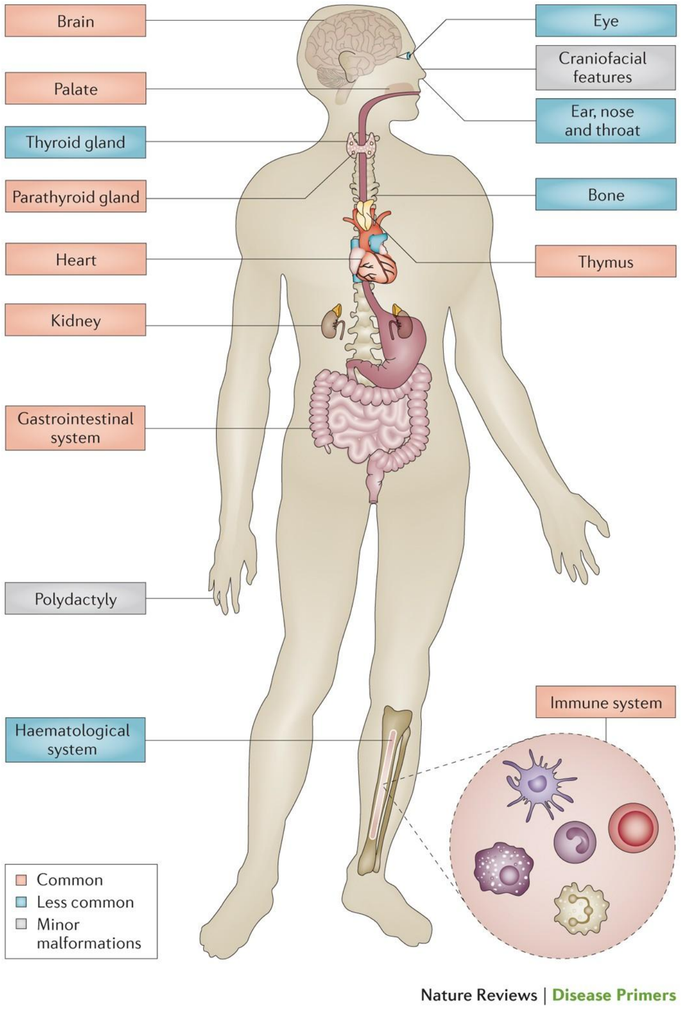
# Functioning in adulthood and integrative care

**Claudia Vingerhoets, PhD**
**22q11 Europe 2025**

# 22q11.2 Deletion



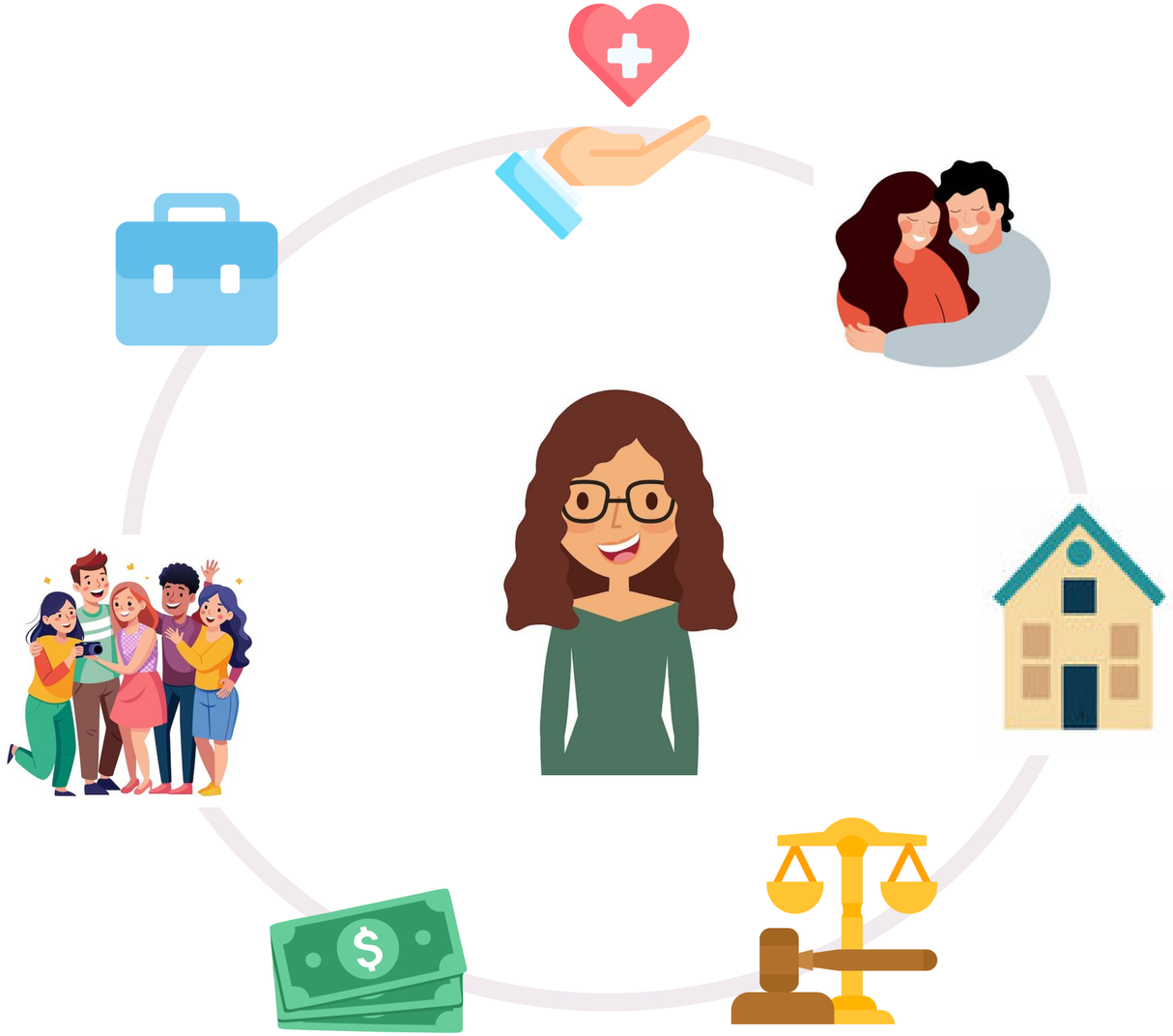

## Physical

- Heart disease
- Immune problems
- Cleft palate

## Brain

- Borderline IQ
  Disharmonious
- Psychopathology
  Anxiety
  Psychosis

# Transition into adulthood



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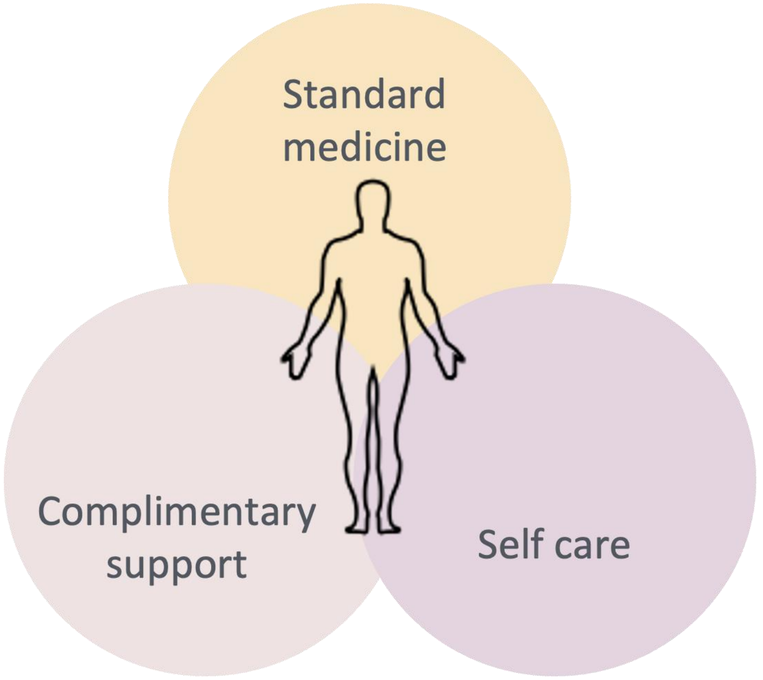
# Integrative care

**Coordinated form of care in which caregivers from various disciplines collaborate to organize a patient's complete care**

- Focus on whole person (body, mind, well-being)
- Improving health and quality of life

Takes into account:

- Needs
- All life domains
- Environment



# Functioning in adulthood

## Levels of functioning

- Adaptive
- Cognitive
- Daily life

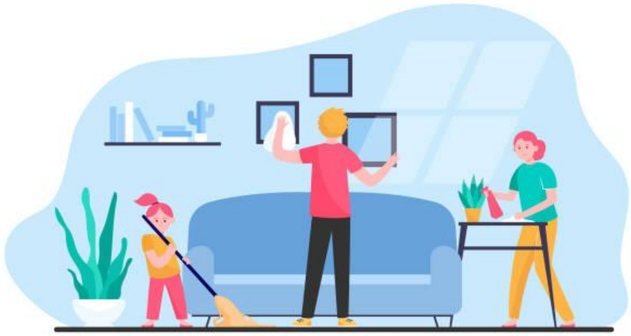
# Functioning in adulthood

| | Total sample | Maastricht | ‘s Heeren Loo | Leuven |
|---|---|---|---|---|
| | 250 | 177 | 57 | 66 |
| | Mean | Mean | Mean | Mean |
| Sex (male/female) | 109/141 | 52/75 | 26/31 | 31/35 |
| Age (years) | 29 | 31 | 32 | 21 |
| FSIQ | 70 | 73 | 63 | 71 |
| VIQ | 71 | 72 | 71 | 71 |
| PIQ | 69 | 69 | 67 | 72 |

Vingerhoets et al. 2024

# Adaptive functioning

## Person’s ability to cope with the demands of daily life

| Communication | Daily living | Socialization |
| --- | --- | --- |
|  |  |  |
| Receptive<br>Expressive<br>Written | Personal<br>Domestic<br>Community | Interpersonal relations<br>Play and leisure<br>Coping skills |

# Adaptive functioning

| | N | % |
|---|---|---|
| High | 0 | 0.0 |
| Moderately high | 1 | 0.6 |
| Adequate | 28 | 17.2 |
| Moderately low | 28 | 17.2 |
| Low | 106 | 65.0 |

| | Standard score | Developmental age |
|---|---|---|
| Communication | 53 | 9;2 |
| Daily living | 69 | 11;4* |
| Socialization | 60 | 9;8 |
| Total | 58 | |

# Adaptive functioning

Female sex

Higher IQ

No ASS diagnosis

Adaptive skills

- Daily living skills
- Overall adaptive functioning

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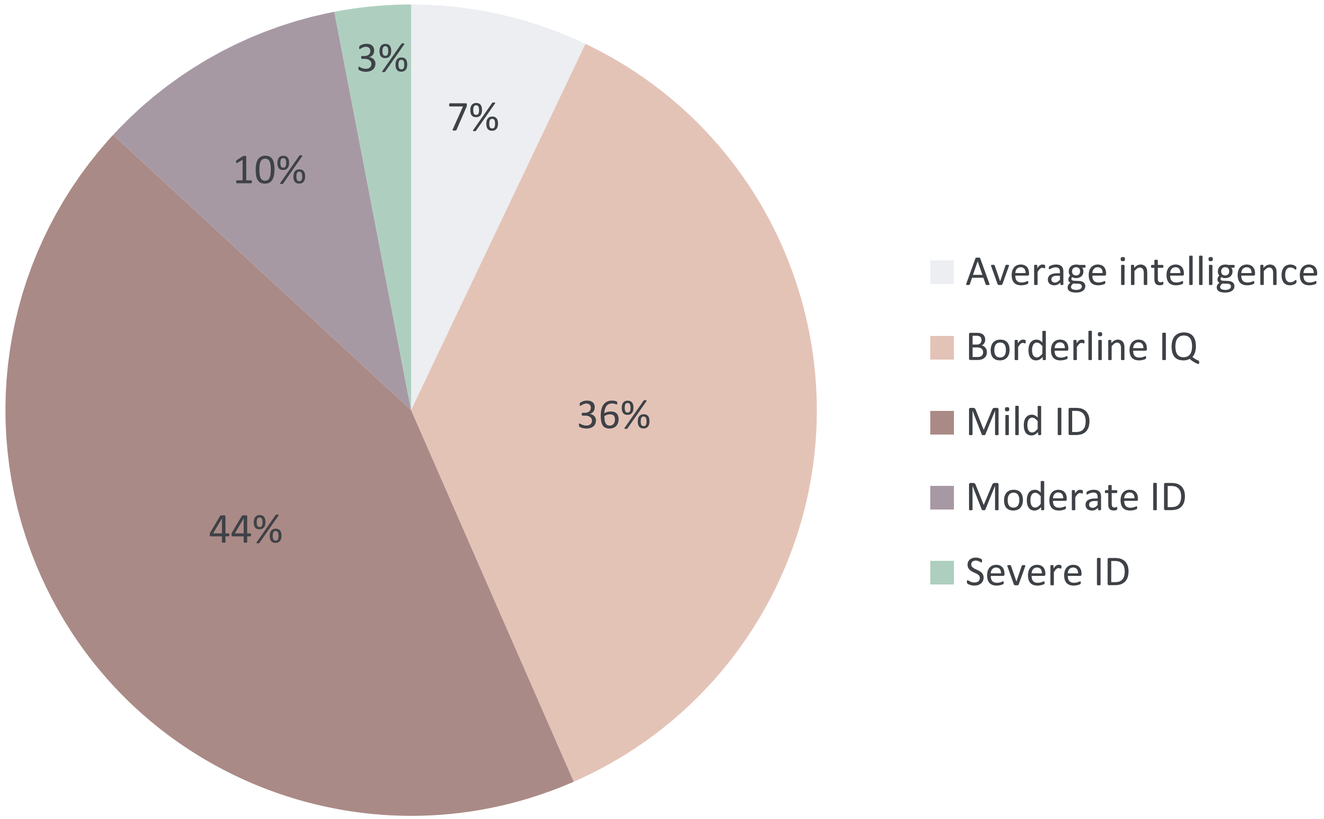
# Intellectual disability

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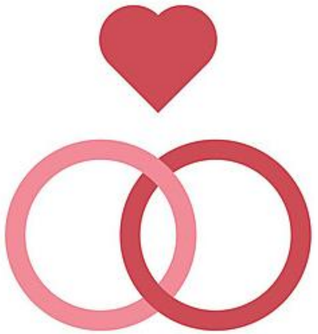
# Daily life functioning

| Marital status | % |
|---|---|
| Single | 76 |
| Married | 13 |
| Long-term relationship | 7 |
| Divorced | 2 |
| Widowed | 2 |



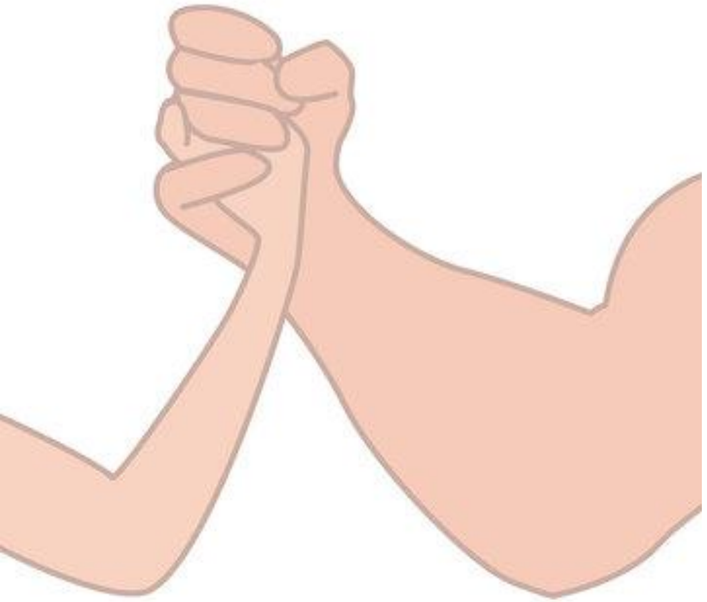
# Daily life functioning

| Living situation | % |
|---|---|
| With parents/family members | 37 |
| With spouse/ own family | 21 |
| ID setting | 20 |
| Independent (alone) | 11 |
| Protected environment (alone) | 5 |
| Psychiatric setting | 4 |
| With roommates | 1 |
| Other | 1 |

# Daily life functioning

| Work | % |
|---|---|
| Day center | 26 |
| Sheltered work | 24 |
| Regular job part-time | 16 |
| Unemployed (no daytime activities) | 10 |
| School | 10 |
| Regular job full-time | 8 |
| Household | 3 |
| Volunteer work | 3 |

# Summary



- Large variability in functioning
- Support/care needs in multiple domains

- Importance of individual assessments!

# Integrative care

- Periodic follow-up
  - Physical and mental health
  - Daily life functioning
- Personalized care/support
  - multiple life domains

- Multidisciplinary team
  - Medical specialist
  - Psychologist
  - Outpatient carer
  - Job coach
  - Occupational therapist
  - Legal guardian
  - Educational support
  - Family carers
- Coordination
- Communication

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# Expertise center ‘s Heeren Loo

**Adults with 22q11 deletion and duplication syndrome**

- Multidisciplinary approach
- Structural collaboration:
  - ID physician
  - Psychologist / educational psychologist
  - Dietician
  - Speech therapist
  - Occupational therapist
- Advisory role/ 2nd opinion
- Research embedded

# Expertise center MUMC

**Adults with 22q11 deletion and duplication syndrome**

- National tertiary clinic
- Multidisciplinary approach
- Structural collaboration:
  - Neurology
  - ENT
  - Opthalmology
  - Biochemistry
  - Orthopedics
  - Psychiatry
- Advisory role/ 2nd opinion
- Research embedded

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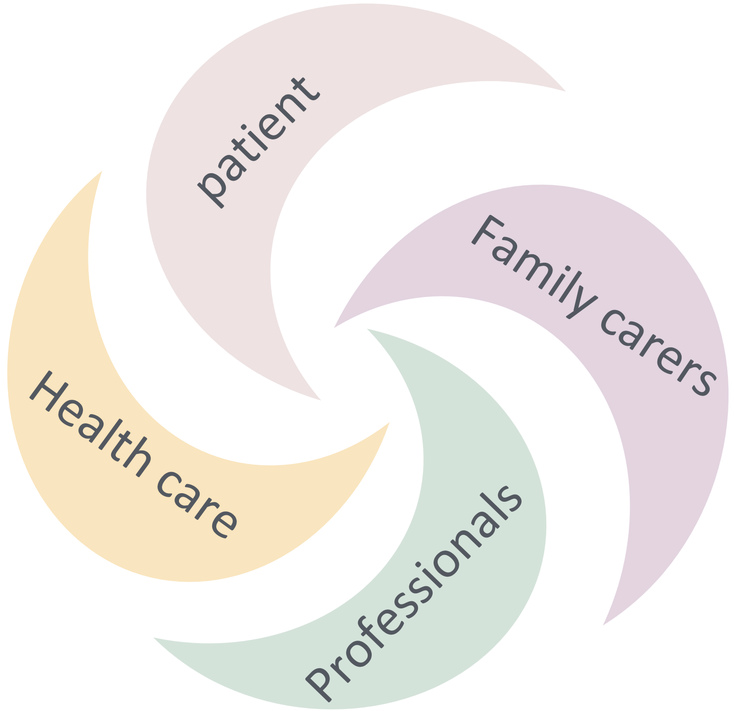
# Take-home messages

- Integrative care based on individual strengths and weaknesses
- Multiple life domains
- Multidisciplinary team



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