

# The Dutch Autism Research Agenda

## OnderZoeksagenda-Autisme



Karin van den Bosch  
Diederik Weve

- Karins Consultancy
- Society of Persons on the Autism Spectrum, PAS



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**ZonMw**

Karins

Consultancy



**PAS**  
Personen uit het Autisme Spectrum



Nederlandse  
Vereniging voor  
Autisme

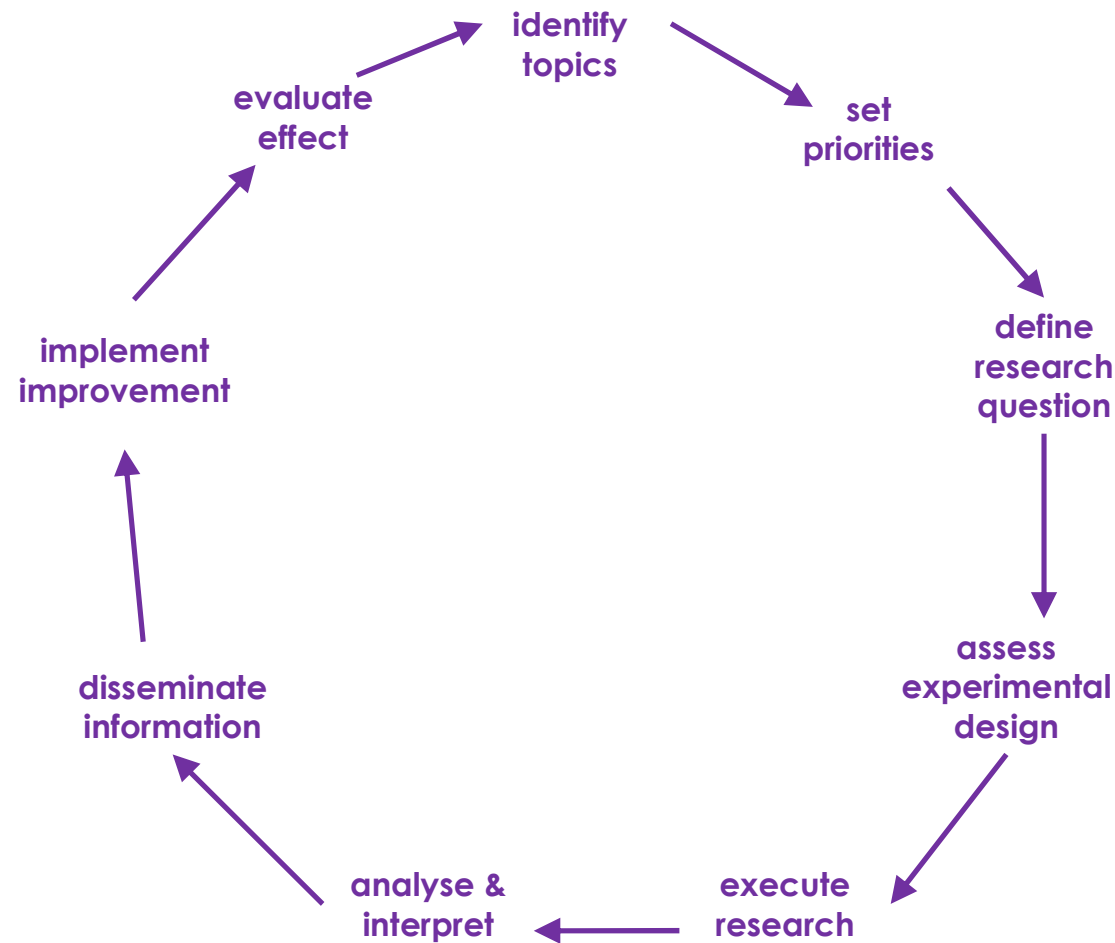
# Structure

- Objectives & Motivation
- Methods
- Results
  - Overview
  - Thematic Analysis
  - Respondent Analysis
- Use of OZA results
- Discussion

# Objectives and Motivation

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# Research Cycle

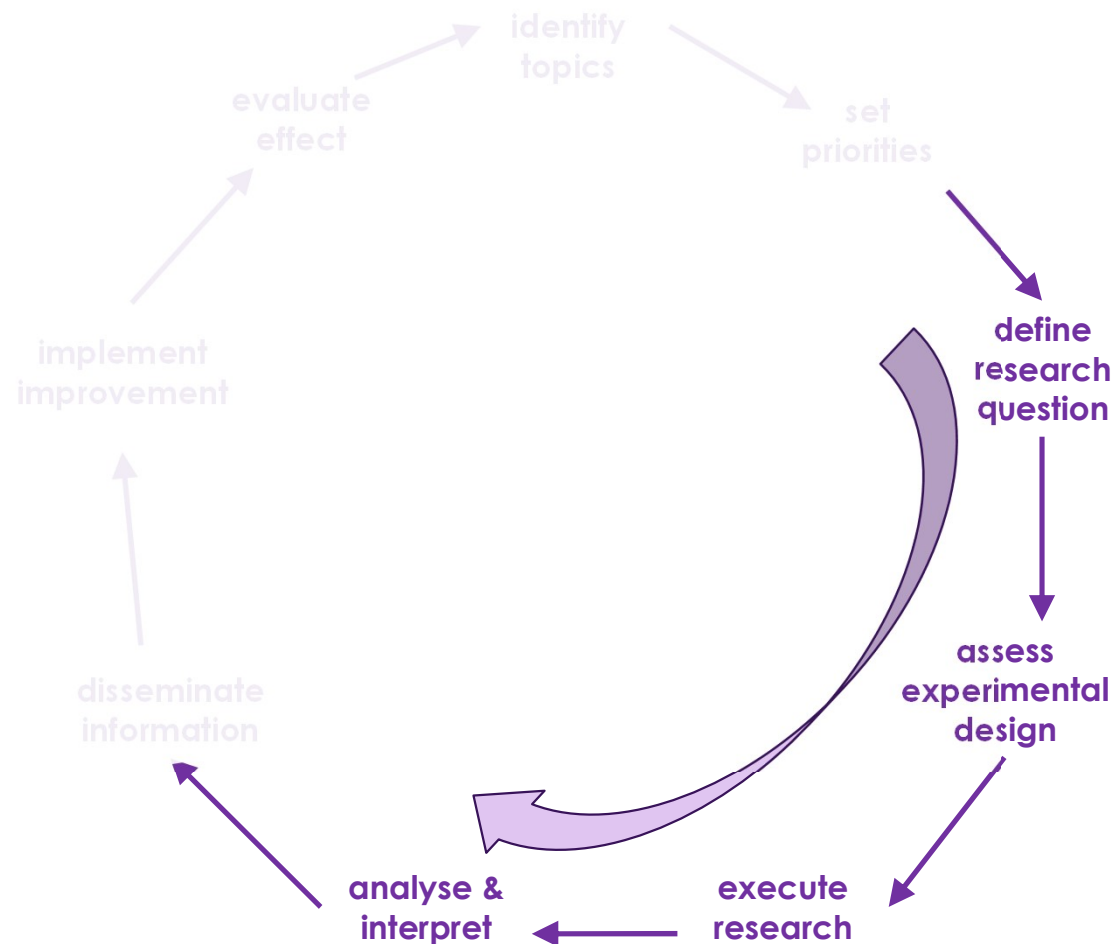


# Research Cycle

Academix Workplaces Autism  
(AWA)

Practitioners & Researchers  
Network & Projects  
funded by Government  
Autistic reps in workgroups

Autistics involved in partial  
research cycle only



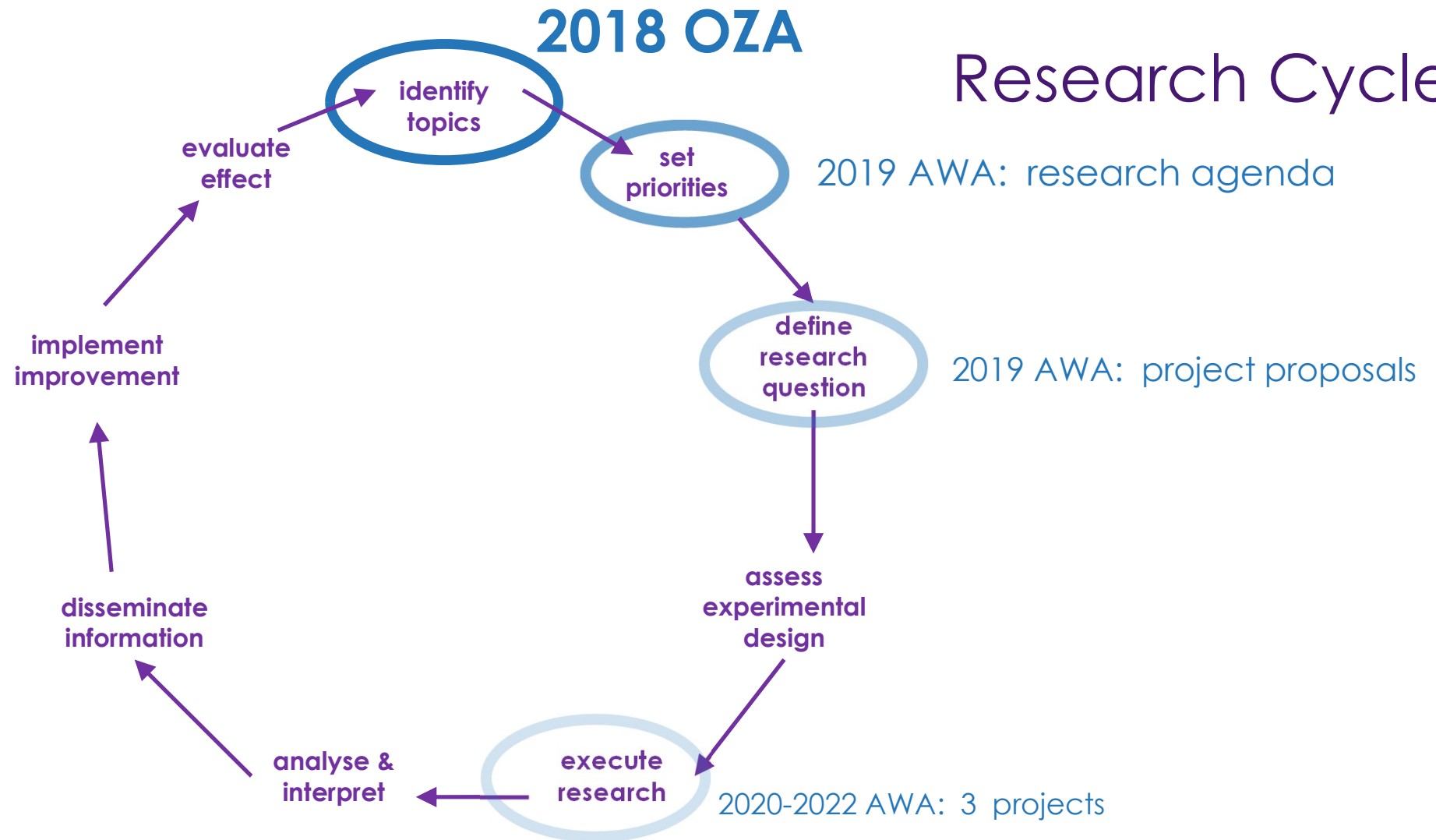
# Motivation NL Research practices

- Pre 2017: Dutch autism research in absence of an overarching research agenda
- Several research groups are mapping available knowledge, knowledge gaps and needs
- Client perspective was not leading in any of these
- Big gap between needs and actual research in UK (Pellicano 2014, Cusack 2018)

# OZA Objectives

- perform large scale inventory of research needs according to
  - autistic adults
  - parents to autistic children
  - legal representatives
  - partners of
- to be used when defining the research priorities (a.o. by Academic Workplaces for Autism)
  - scientific methods
  - qualitative & quantitative analysis
  - incorporating feedback from focus groups
- sponsored by ZonMw (Dutch Healthcare Research Institute)
- started 2017, final report Spring 2019

# Research Cycle





# Methods

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# Methods Survey

- Open question inserted in the 2018 NAR longitudinal survey:  
**“What, according to you, should be investigated in the field of autism?”**
- Closed Questions on the target groups for such research  
**“For which groups is this research intended?”**
  - Gender, Age, IQ, minoritygroups (culture, LGBT, other)
- Send to 2444 NAR participants, 923 responses (38%)
  - 695 autistic adults
  - 166 parents
  - 62 legal representatives
- Use supplementary NAR socio-demographic respondent data

# Methods Analysis

- Mixed methods approach:
  - Qualitative: inductive thematic analysis of the open question
    - Blind
    - Identify topics in each response
    - Thematic analysis
    - Coded using MAXQDA
  - Qualitative analysis
    - Numerical analysis of Wording, Themes and Socio-demographic data
    - Effects of the role of the respondent
    - Demographic analysis
    - using SPSS

# Methods

## Identification of topics

[Research into:]

“**Living** using **(forms of) support** for **adults 30+** with **normal intelligence**”

We did not want to use standard lists of categories or themes

# Methods

## Thematic analysis




What structure can be brought to these replies ?



# Methods

## Thematic analysis

Painter will sort on:  
colour

1<sup>st</sup> brown   

2<sup>nd</sup> gray  

3<sup>rd</sup> pink 

Researcher sorts on  
knowledge domains?

Economist will sort on:  
use

1<sup>st</sup> recreational   

2<sup>nd</sup> households  

3<sup>rd</sup> food 

Policy makers sort on  
benefits?

Zoo-keeper will sort on:  
type of food

1<sup>st</sup> carnivore   

2<sup>nd</sup> omnivore  

3<sup>rd</sup> herbivore 

Autistics sort on  
needs & meaning?

# Methods

## Thematic analysis

- Identification and grouping of topics in an full tekst response is about interpretation
  - Choices must be made
  - These choices influence the research results
- What meaning is given and how is it worded
- How do topics relate to each other
- Sometime the transition between categories is fluent

# Results

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# Results - Theme example

## Traits, Complaints & Comorbidity

- Some themes reflect graduation in language used

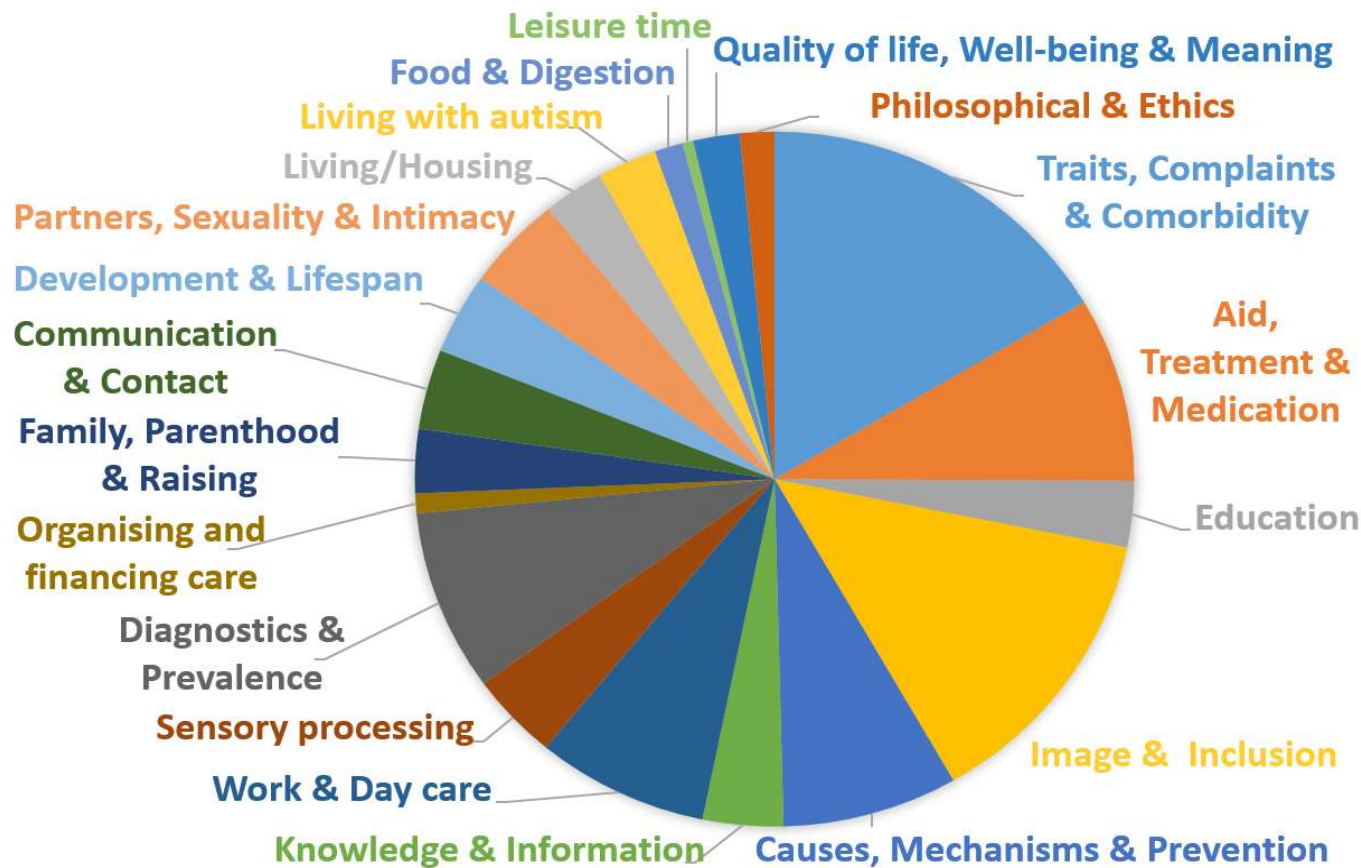
Trait	Complaints	Comorbidity
neutral	negative	medical diagnosis
"...autism and eating behaviour..."	"...problems with eating..."	"...eating disorders..."

# Themes

pie chart for  
autistic adults only

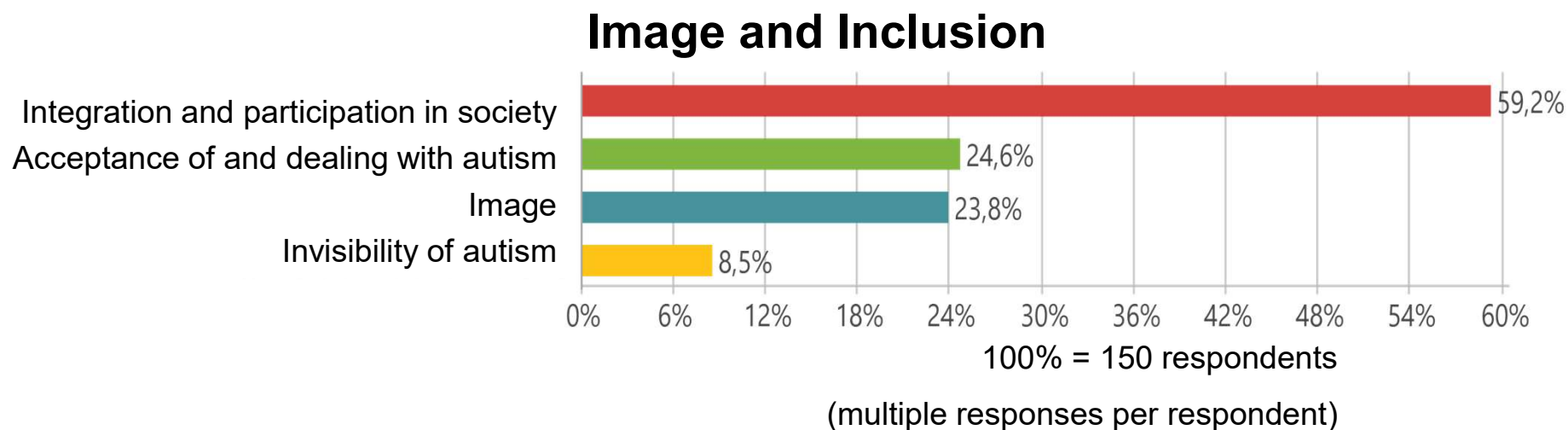
n=695

M/F/X = 289/403/3

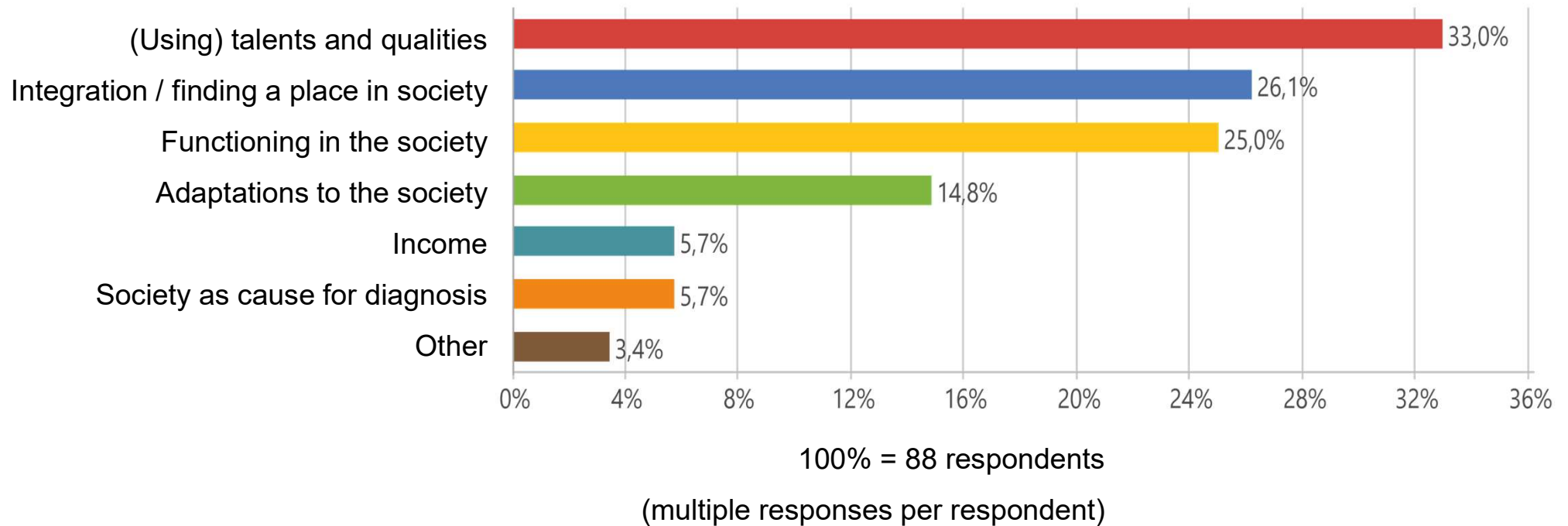


# Results: Image & Inclusion Respondent Analysis

- named by 150 respondents (16%)
  - 130 adults (19% of adults)
  - 17 parents (10% of parents)
  - 3 legal reps (5% of legal reps)



## Integration and participation in society



# Results

## Respondent analysis - Image & Inclusion

### Theme mentioned especially by:

- **role: adult autistics**
- gender: -
- age: -
- **IQ: higher than average**
- **ethnicity: non-Dutch**
- **relation: yes**
- Highest education: -
- Primary income & working hours: -
- AQ & Age of diagnosis: -
- wellbeing: -
- **treatment satisfaction: low**
- ....

### Subtheme mentioned especially for:

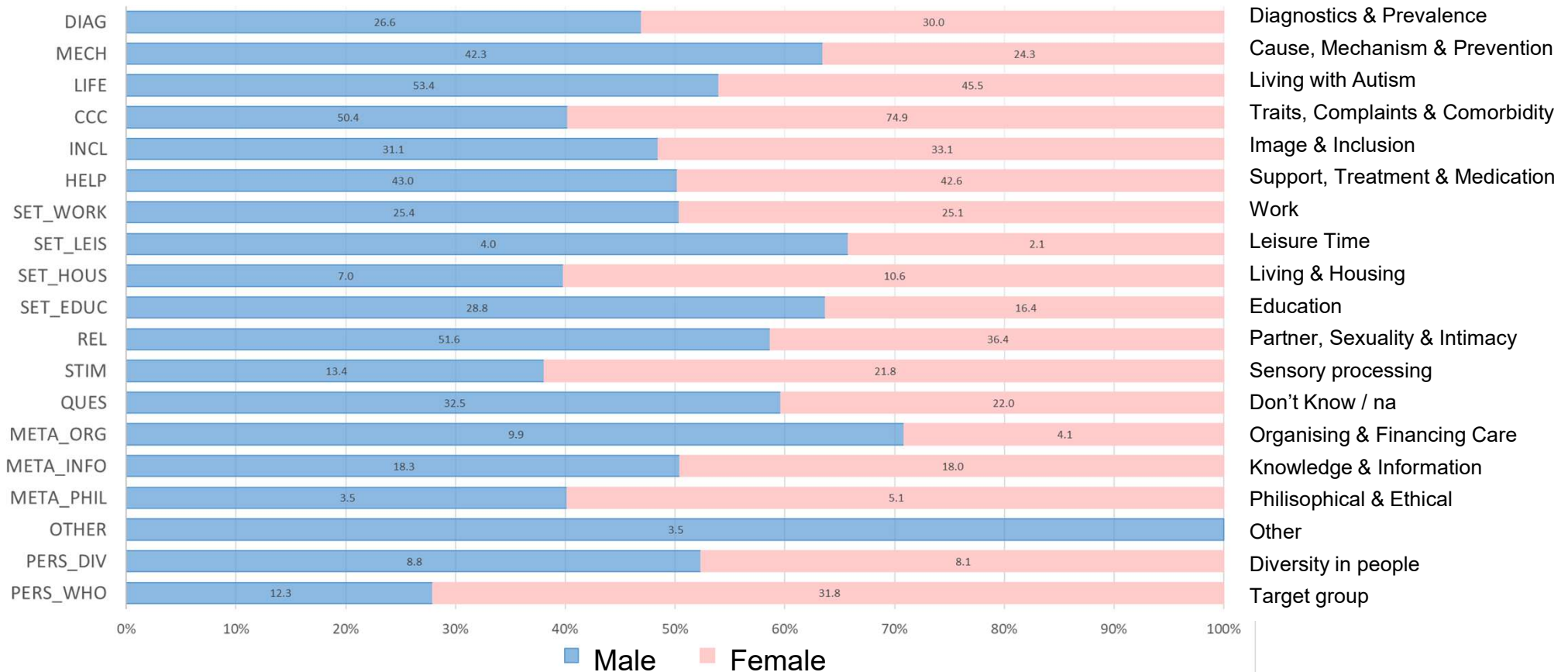
- Integration & Participation:
  - non-western and LGBT
  - IQ: normal IQ is under-represented
- Image:
  - non-western and LGBT
- Acceptance of own autism & Dealing with:
  - others (specified free tekst)

 a broadly supported theme

onderzoeksagenda autisme

# Role of Gender

Gender based response  
corrected for group size

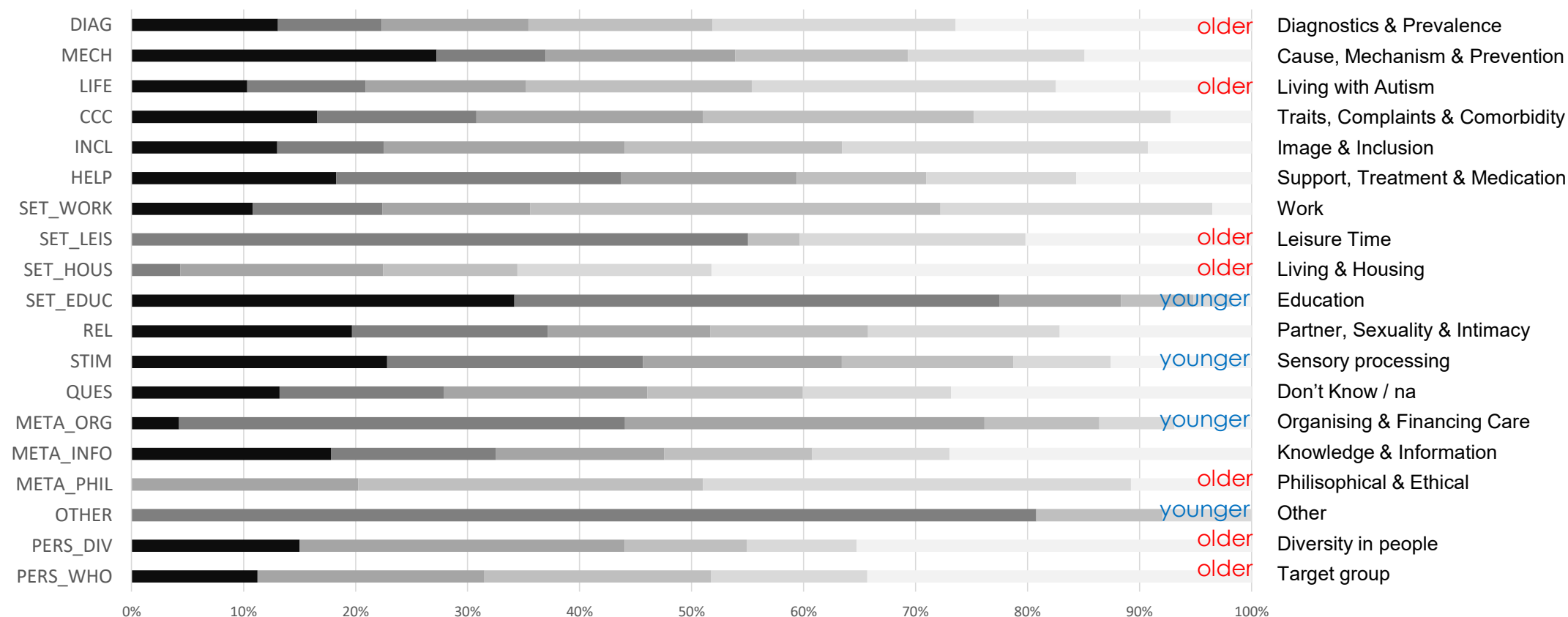


Diagnostics & Prevalence  
Cause, Mechanism & Prevention  
Living with Autism  
Traits, Complaints & Comorbidity  
Image & Inclusion  
Support, Treatment & Medication  
Work  
Leisure Time  
Living & Housing  
Education  
Partner, Sexuality & Intimacy  
Sensory processing  
Don't Know / na  
Organising & Financing Care  
Knowledge & Information  
Philosophical & Ethical  
Other  
Diversity in people  
Target group

Age based response  
corrected for group size

# Role of Age

■ 4-12 ■ 13-16 ■ 17-29 ■ 30-49 ■ 50-64 ■ 65+



# Discussion

## OZA

- clear effect of participatory research in theme identification
- clear differences between different stakeholder groups and the current research preference
- theme-survey reveals clear stakeholder group profiles and common items (Top 5 has 3 common and 2 unique items for each stakeholder group)
- research should cover wider areas and become more multi-disciplinary

## AWA-2

- priority questionnaire extended stakeholders (e.g. teachers, civil servants, health-prof)
- priorities are generally matching OZA results
- selected 3 themes for research projects:
  - Image & Inclusion
  - Support, Care & Medication
  - Living with (own) autism



# Questions?

presentation



full report (Dutch)



- Project
    - Karin van den Bosch
    - Diederik Weve
  - Steering committee:
    - Bernadette Wijnker (NVA)
    - Sander Begeer (NAR)
    - Arjan Stoffels (PAS)
- **Email: [info@onderzoeksagenda-autisme.nl](mailto:info@onderzoeksagenda-autisme.nl)**
  - **Website: [www.onderzoeksagenda-autisme.nl](http://www.onderzoeksagenda-autisme.nl)**

