Research needs of autistic adults, parents of autistic children and legal representatives

OZA, “Research Agenda Autism"

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Structure

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

Motivation
NL Research practices

- Until 2017: Dutch autism research in absence of an overarching research agenda

- Several groups are mapping available knowledge, knowledge gaps and needs
  - Academic Workplaces Autism (planning AWA project continuation)
  - Nederlands Autisme Register (closed question survey among clients)
  - Erasmus University project Diversity & Autism (analysis of scientific literature & surveys)

- Client perspective was not leading in any of these

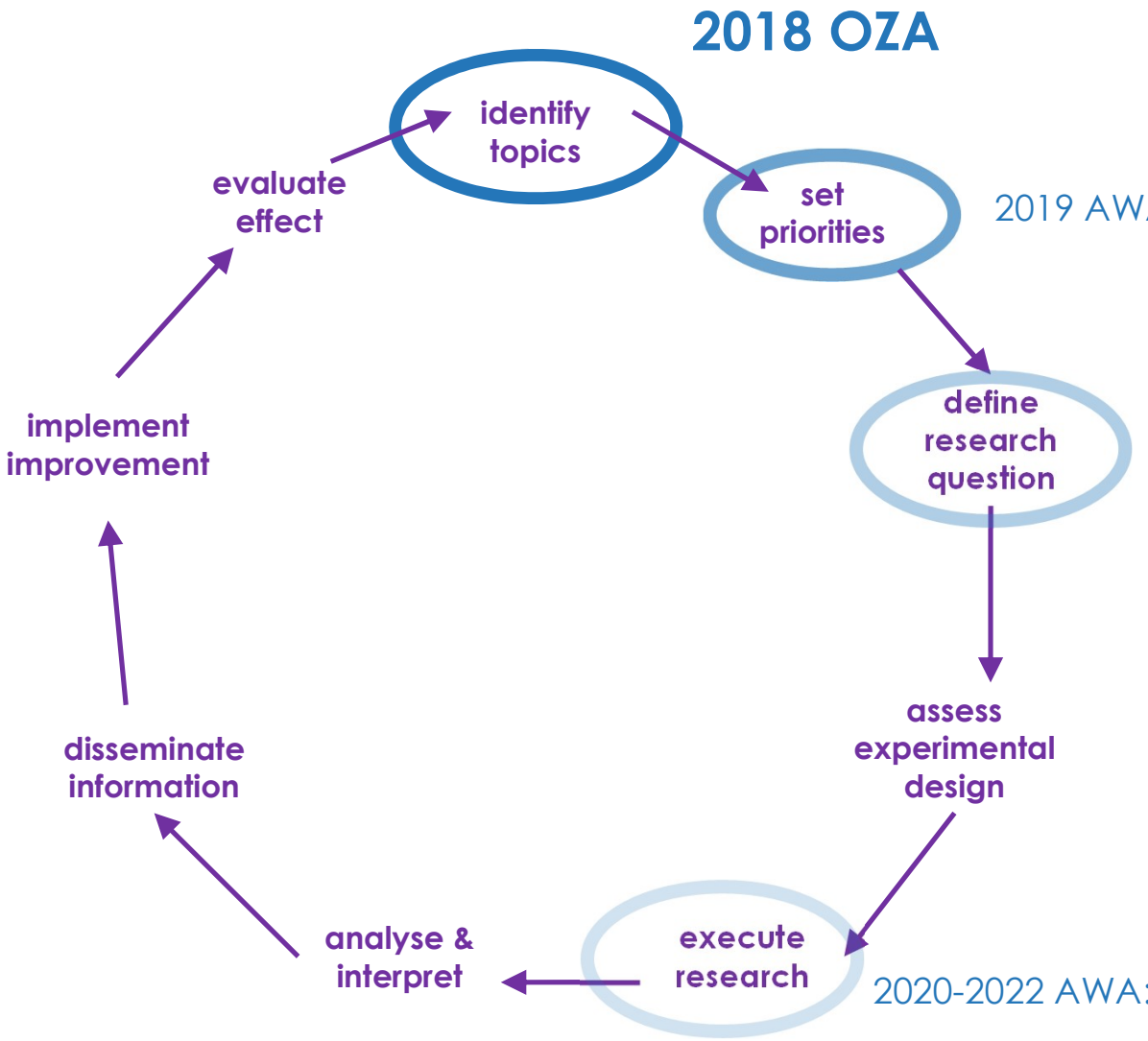
Motivation
Autistic research needs

- Big gap between needs and actual research in UK (Pellicano 2014, Cusack 2018)
- Pelicano
  - themes: workshops (14 autistics = 20%)
  - priorities: online survey for 11 research proposals (122 autistics = 7%).
- Autistica (Cusack e.a.)
  - themes: online 1213 (autistics ?%, parents, prof) respondents analysed to 89 questions
  - priorities: 1375 from 25 top research questions
  - workshop: 10 research questions by consensus

OZA Objectives

- started 2017, final report Spring 2019
- 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)

Research Cycle



2019 AWA: research agenda

2019 AWA: project proposals

2020-2022 AWA: 3 projects

onderzoeksagenda autisme

ZonMw Karins Consultancy PAS Personen uit het Autisme Spectrum nar Nederlands Autisme Register NVA Nederlandse Vereniging voor Autisme

Methods
Survey

- Mixed methods: qualitative + quantitative
- 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 respondent data (a.o. demographic) from regular NAR

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
    - Demografic analysis
    - using SPSS

Methods
Identification of topics

[Research into:]

- *"Living using (forms of) support for adults 30+ with normal intelligence"*

Methods
Identification of topics

[Research into:]

- *"**Living** using **(forms of) support** for **adults 30+** with **normal intelligence**"*

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

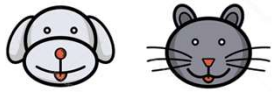
Methods
Thematic analysis

What structure can be brought to these replies ?

Methods
Thematic analysis

Painter will sort on: colour

1st brown

2nd gray 

3rd pink

Researcher sorts on knowledge domains?

Economist will sort on: use

1st recreational

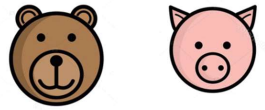
2nd households

3rd food

Policy makers sort on benefits?

Zoo-keeper will sort on: type of food

1st carnivore

2nd omnivore 

3rd herbivore

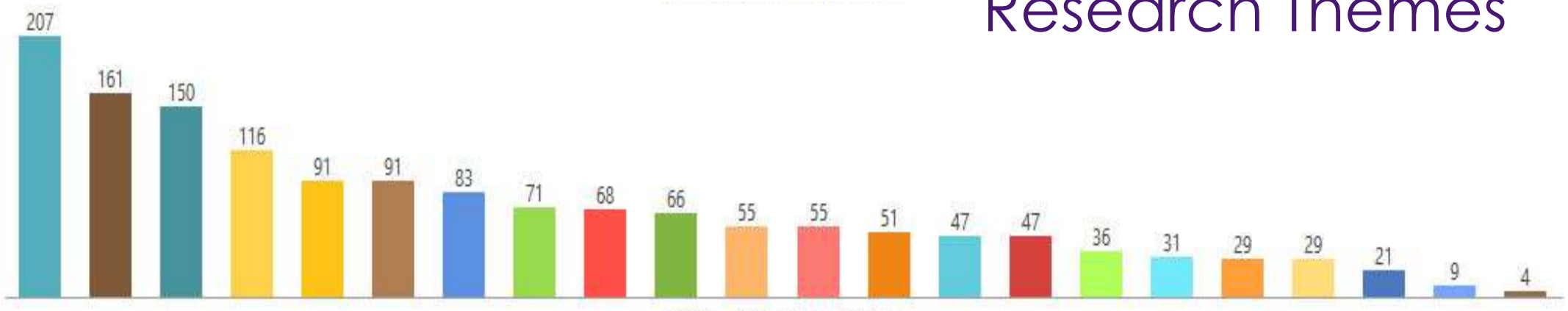
Autistics sort on needs & meaning?

Methods
Thematic analysis

- What meaning is given and how is it worded
- How do topics relate to each other

- Categorial attribution is not always black & white
- Sometime the transition between categories is fluent

Results
Research Themes



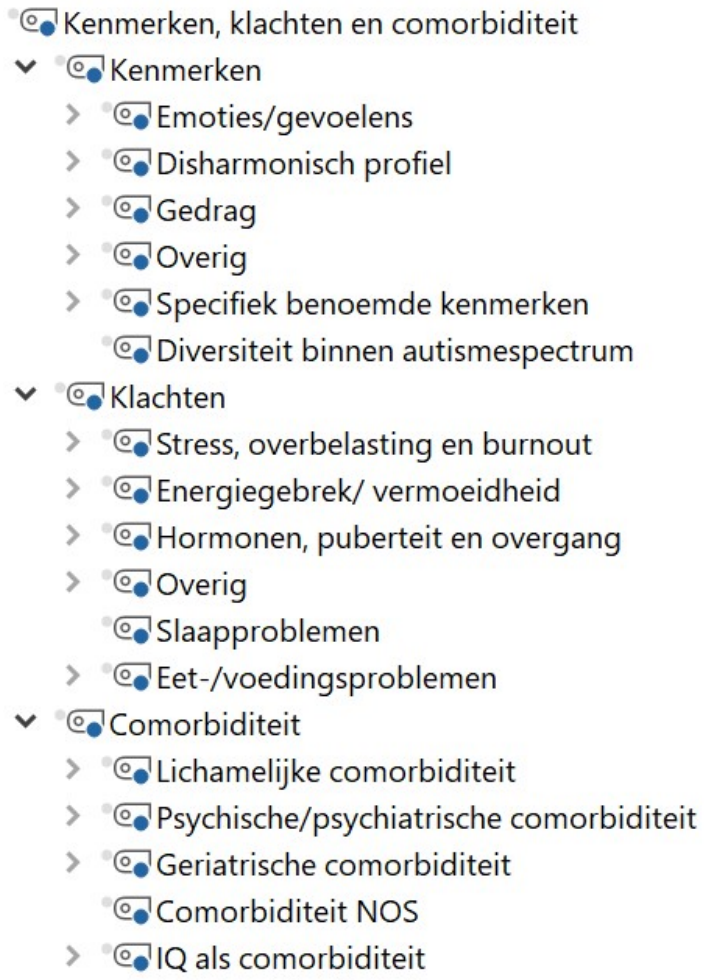
923 respondents

(multiple responses per respondent)

- Traits, Complaints & Comorbidity
- Support, Treatment & Medication
- Image & Inclusion
- Living with Autism
- Diagnostics & Prevalence
- Work
- Cause, Mechanism & Prevention
- Education
- Knowledge & Information
- Target group
- Don't Know / na
- Sensory processing
- Family, Parenthood & Raising
- Partner, Sexuality & Intimacy
- Communication & Contact
- Diversity in people
- Living/Housing
- Organising & Financing Care
- Digestion & Food
- Philisophical & Ethical
- Leisure time
- Other

23 Themes & 906 subthemes

- Huge diversity in themes
- Diversity within the themes
  - Multiple levels in subthemes (3-5)
- Selection of some themes may feel odd where these ignore existing disciplines and the boundaries that deleneate them.



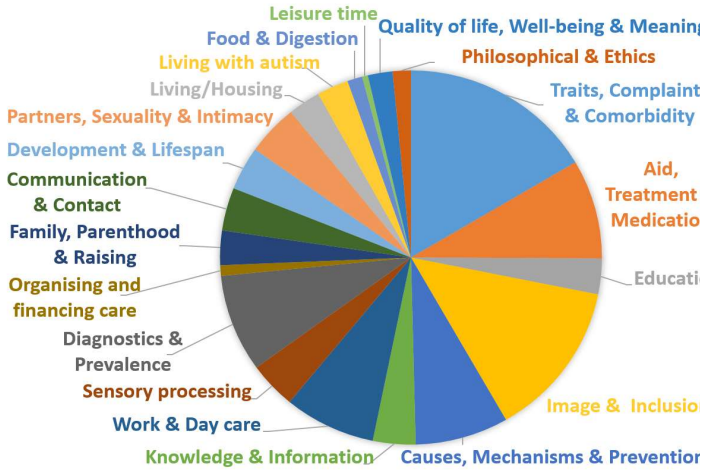
Results - Theme example
Traits, Complaints & Comorbidity

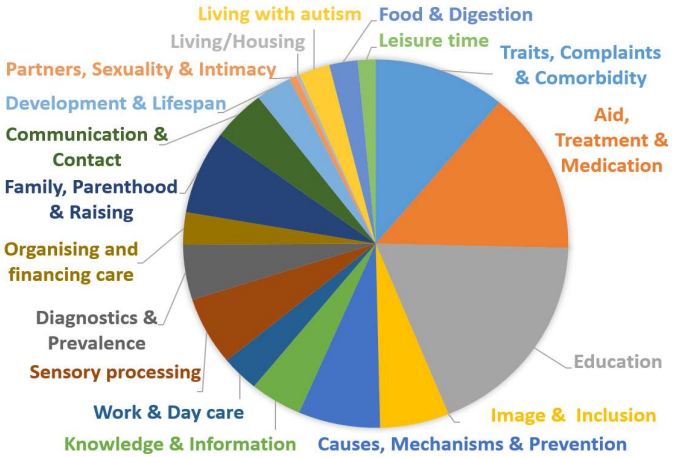
- Gradual transition between trait (neutral), complaint (negative) and comorbidity (officially recognised disorder, diagnosis)

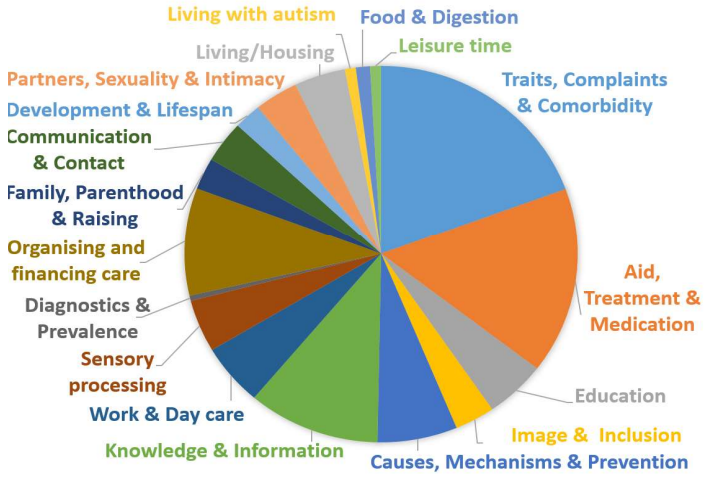
- Reflects use of language: ('autism and eating behaviours' – 'problems with eating' – 'eating disorders')

Results
Themes per respondent group

Autistic Adults	Parents	Legal representatives
n=695	n=166	n=62
M/F/X 289/403/3	M/F/X 133/33/-	M/F/X 45/17/-



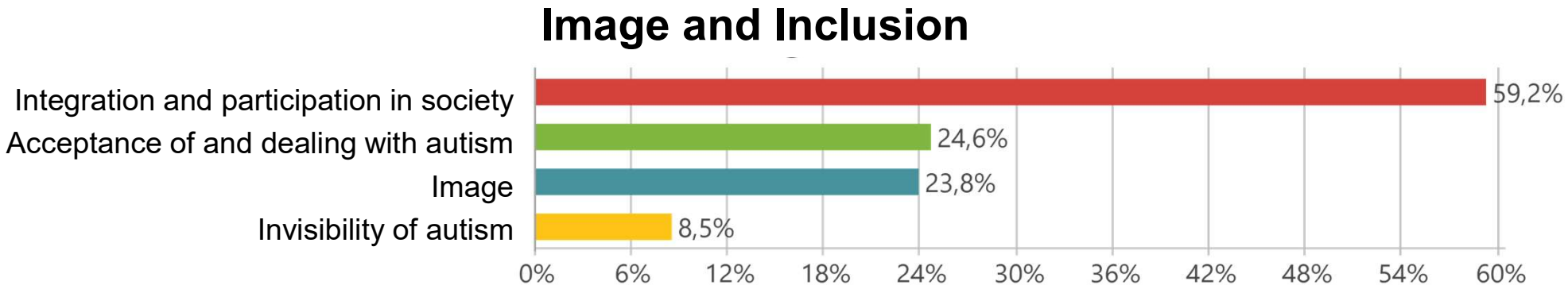




Results: Image & Inclusion Respondent Analysis

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

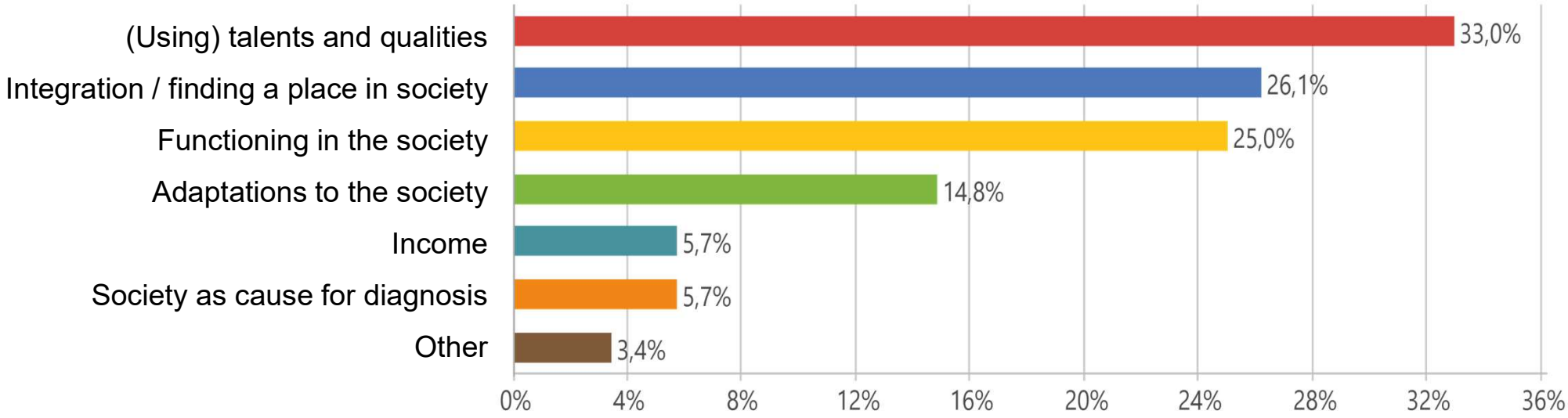
Results
example subthemes



100% = 150 respondents

(multiple responses per respondent)

Integration and participation in society



100% = 88 respondents

(multiple responses per respondent)

Results
Integration and participation

	Number (% norm.)	Important subthemes	Example
Adults	77 (11%)	Using qualities (in society) functioning	"(…) When more scientific research is done on the potential of autism then it can be demonstrated exactly here that autism can be very valuable to society. This will result also in that autistics meet more understanding and develop more self respect"
Parents	9 (5%)	Integration / place using qualities	"How can children/people with autism can come along as good as possible in the contemporary society so that they are accepted and can also make a valuable contribution themselves."
Legal representatives	2 (3%)	Integration / place using qualities	"Because of their problems, some of the children cannot participate in any form of social intercourse (group-care, specialized sports clubs / clubs etc.). (...) How do these children find their place in society?"

Results
Respondent analysis

- Themes can be understood better when a respondent profile can be determined
  - Who mentioned the theme
  - For whom was it intended
- NAR has +/- 1200 socio-demographic datapoints per respondent
- 15 properties were selected for analysis (gender, age, IQ, AQ, relation, income, housing, education, somatic & mental comorbidities,wellbeing, ethnicity,….)

Results
Respondent analysis - Image & Inclusion

<u>Theme</u> mentioned especially by:

- role: adult autistics
- gender: -
- age: -
- IQ: -
- etnicity: Dutch is under-represented
- relation: yes
- Highest education: -
- Primary income & working hours: -
- AQ & Age of diagnosis: -
- welbeing: -
- treatment satisfaction: low
- ….

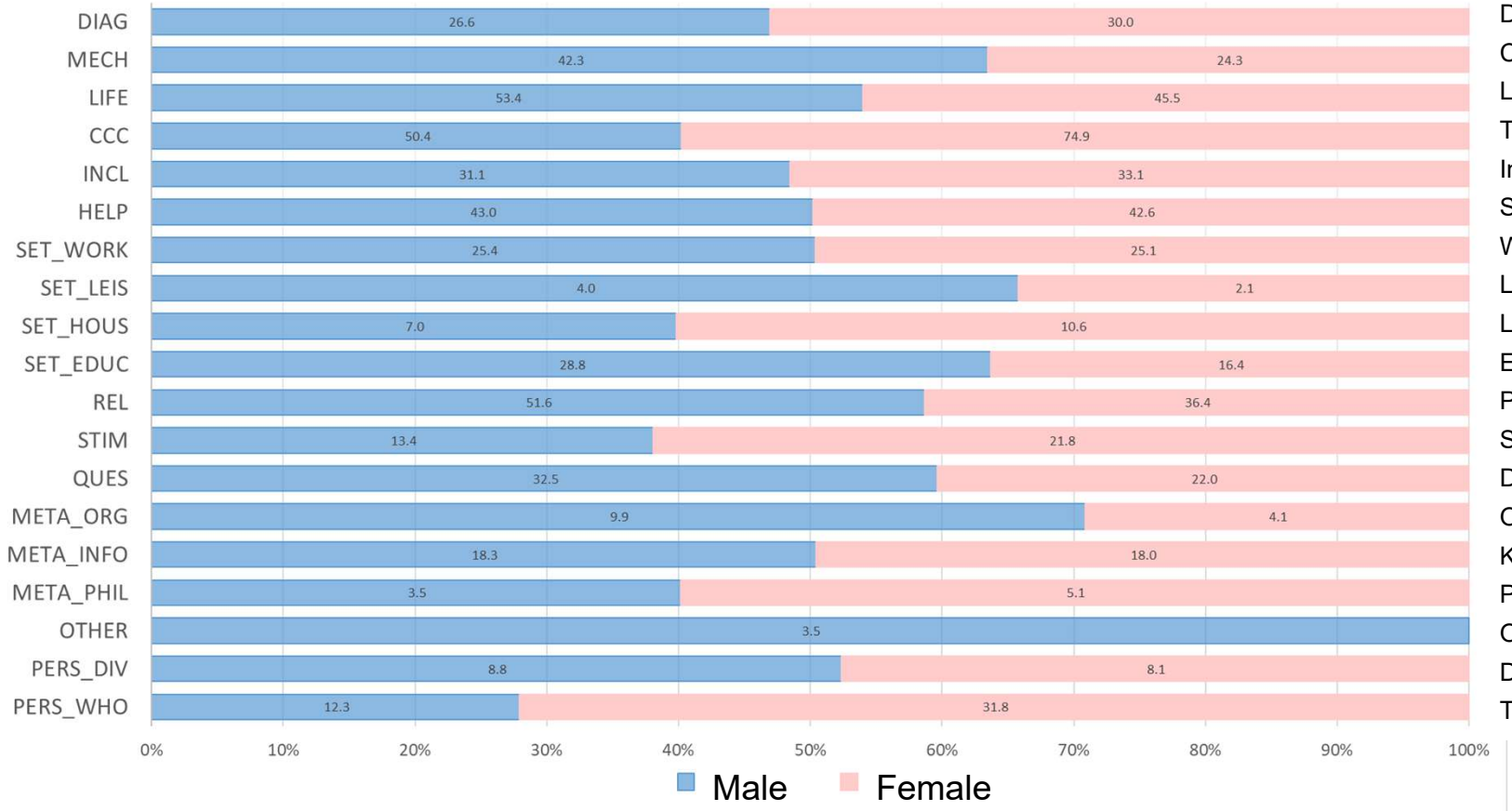
→ a broadly supported theme

<u>Subtheme</u> 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)

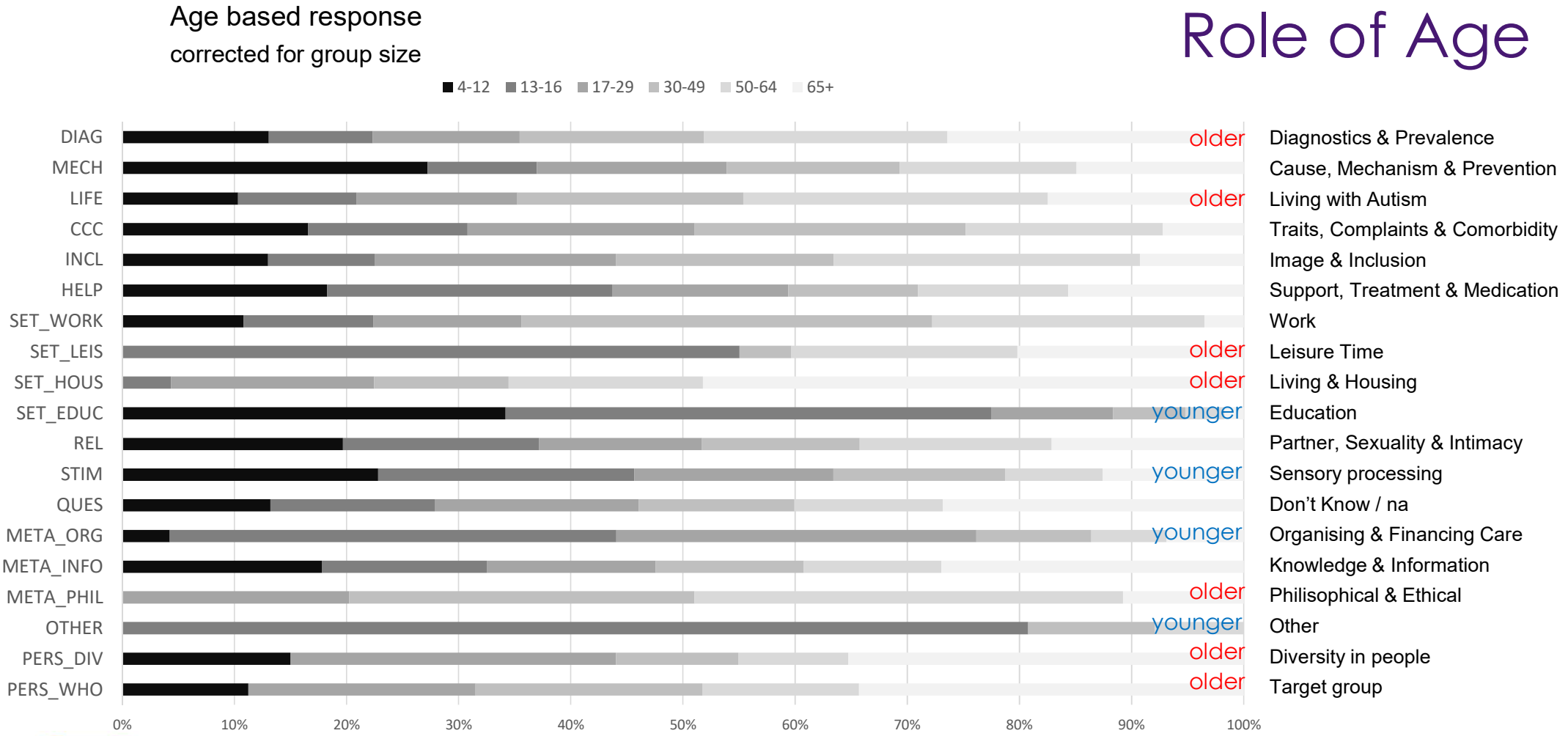
Role of Gender

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
Philisophical & Ethical
Other
Diversity in people
Target group

Role of Age



onderzoeksagenda autisme

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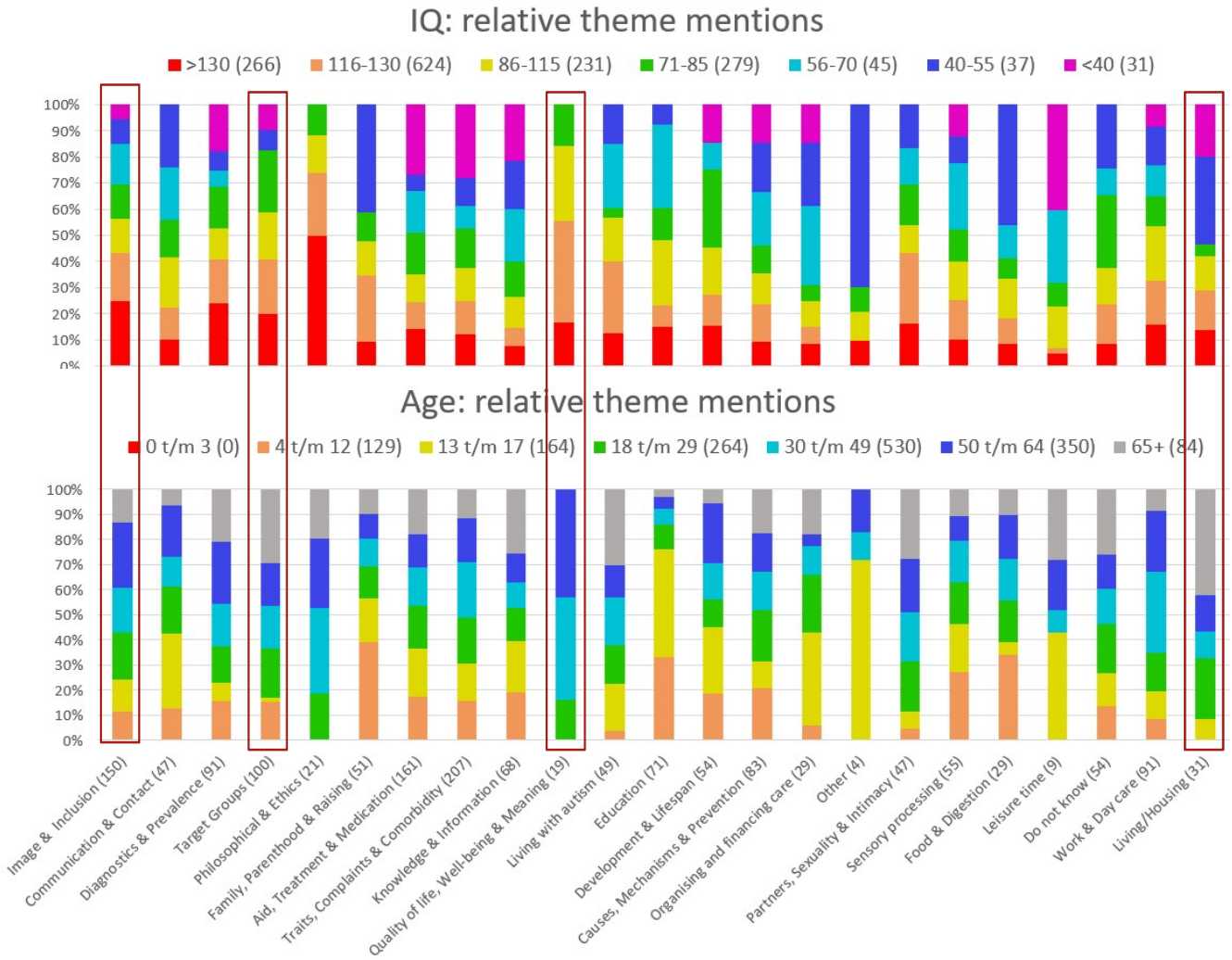


- NAR socio-demografische data helps to understand themes
- sommige themes have a clear profile
- we know the profiles of the group
  - who gave the response
  - whom did they target

- profiles can deviate from mainstream research effort
  - e.g. diagnostic research should be especially for women with normal/high IQ, more specifically for older women with higher IQ (instead of babies)

Occasional statistical findings (example: work)

Who mentions the theme 'Work'?

GENDER	Mentions Work
Male	5.4%
Female	5.5%

→ no effect of gender

ROLE	Mentions Work
Adult	6.2%
Parent	2.7%
Legal Rep	5.2%

→ parents clearly lagging
?primary focus on education as precursor to work?

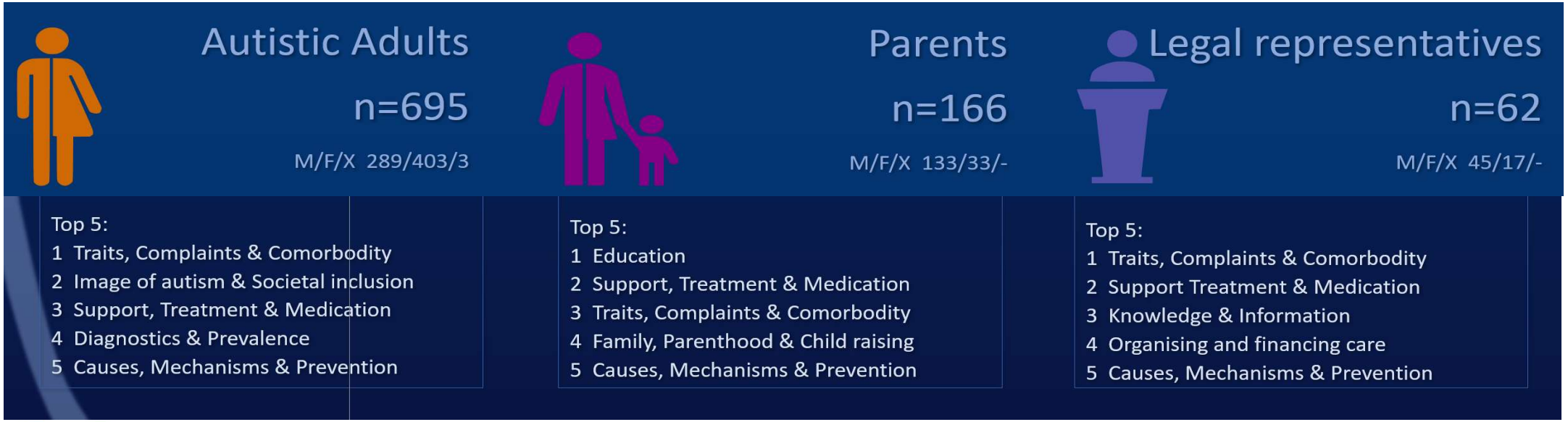
	Adults		Parents		Legal Representatives	
	Male	Female	Male	Female	Male	Female
Population	289	403	133	33	45	17
Mentions Work	17.8	25.1	4.4	0	3.3	0
%	6.2%	6.2%	3.3%	0.0%	7.3%	0.0%

→ but parents and legal representatives mention work <u>only</u> if they have an autistic son

Model: adj R^2 0.020 β -0.144 p=0.03 significant

Conclusions

- More diverse themes than expected and currently researched by autism professionals
- To address client mentioned themes we need new, interdisciplinary research
- Significant differences as well as overlap between respondent groups



AWA

Use of OZA in Academic Workplace Autism

AWA is government sponsoring of networks for applied autism research

Universities, Health care providers and stakeholders (PAS Nederland, NVA)

- AWA-2 (2019 – 2022) subsidy round
  1. must create a broadly supported research agenda for use in Netherlands
  2. propose broadly supported research projects to be sponsored in AWA.
  3. execute projects with participation of clients

  1. Collect priorities while extending stakeholder groups with partners of, professionals (research, eduction, care, policies)
     - Expectation to be based on OZA Results
     - Online survey (N=1160, autistics=649)
     - panel discussions (N=25)
     - steering committee selects top priorities (PAS & NVA have double votes)
  2. Propose AWA-2 projects
     - AWA participants draft proposals
     - steering committee advises (PAS & NVA have double votes
     - AWA research coordinators select research proposal OZA-2

AWA
marks per stakeholdergroup

Thema's	ASD (n = 649)	Next to (n = 631)	Health prof. (n = 482)	Researcher (n = 63)	Educ. prof. (n = 94)	Policy maker (n = 50)
Other (specified)	7,9	8,3	8,2	9,6	9,8	9,5
Communication and contacts	7,6	8,1	8,2	8,0	8,3	8,7
Living with Autism	8,5	8,4	8,1	7,8	8,1	8,4
Image & Inclusion	8,0	8,1	8,0	8,1	8,0	8,6
Support, Treatment & Medication	7,9	8,4	8,1	7,7	8,1	8,2
Education	7,3	8,4	8,1	7,9	8,6	8,1
Knowledge & Information	8,0	8,2	8,1	7,4	8,1	8,1
Quality of Life	7,8	8,1	8,0	7,9	7,9	8,2
Sensory processing	8,0	8,1	8,0	7,1	8,0	8,1
Family and Parenting	6,5	8,2	8,1	7,7	7,9	8,4
Work	7,5	7,9	7,7	7,1	7,8	8,2
Traits, Complaints & Comorbidity	7,9	7,7	7,7	7,1	7,5	7,6
Diagnostics & Prevalence	7,7	7,6	7,6	7,1	7,4	7,5
Development and aging	7,6	7,9	7,7	7,2	7,3	7,5
Living & Housing	6,9	7,7	7,4	6,8	7,1	7,9
Organising & Financing Care	6,9	7,6	7,3	6,4	7,1	7,3
Cause, Mechanism & Prevention	6,6	6,9	7,2	6,7	6,8	7,6
Partner, Sexuality & Intimacy	6,8	7,1	7,1	7,1	6,8	7,0
Leisure Time	6,3	7,1	7,0	6,1	6,8	7,5
Food and Digestion	6,7	7,0	6,9	5,7	6,8	6,6
Philisophical & Ethical	6,2	6,3	6,6	6,7	6,3	6,9

AWA-2
selected themes & project proposals

- 3 large projects for themes:
  - Living with (own) autism
  - Support, Care & Medication
  - Image & Inclusion

- Quality of life should receive attention in all these projects

- The theme 'Education' will be covered by the recently started project 'The inclusive school'

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-disciplinairy

AWA-2

- priorities are generally matching OZA results
- Yielded –unfortunately- only a single research proposal per theme
- Continuing risk of researcher bias towards their own domains (skill and experience)

Questions?

Info

- Project
  - Karin van den Bosch
  - Diederik Weve
- Steering committee:
  - Bernadette Wijnker (NVA)
  - Sander Begeer (NAR)
  - Arjan Stoffels (PAS)

  - **Email: info&onderzoeksagenda-autisme.nl**
  - **Website: www.onderzoeksagenda-autisme.nl**