

Autism research into *what...?*

Autism research needs according to Dutch autistic adults, parents and legal representatives

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Introduction

Research conducted in the UK (Pellicano, Cusack) showed a disconnection between autism research themes set by researchers and funders, and the research needs of the English autism community. But what about the Dutch autism community? In this study we directly asked those who live with (a family member with) autism on a daily basis: 'What should autism research focus upon?'. This study aims at identifying themes as a first step for setting research priorities by the Dutch Academic Workplace Autism (AWA).

Methods

In 2018 we added a questionnaire to the longitudinal online survey of the Netherlands Autism Register (NAR), including the open question: 'What should autism research focus upon?'. Responses from autistic adults and from parents and legal representatives were analysed using a mixed methods approach. Open answers were analysed using inductive thematic analysis. Quantitative techniques were used to compare group responses and correlate to socio-demographic data. A steering group with representatives of PAS Nederland, NVA and NAR guided the process. Focus groups comprising of autistic adults, parents and legal representatives commented on the data-analysis and decision process.

Results



Autistic Adults
n=695
M/F/X 289/403/3

- “ Consequences of a diagnosis in old age (above 50).
- “ What is needed to make this society friendlier, a place in which people with autism feel welcome too?
- “ Understanding 'normal' people with autism, who have invisible complaints. How does the environment perceive this and what can be improved in their understanding?



Parents
n=166
M/F/X 133/33/-

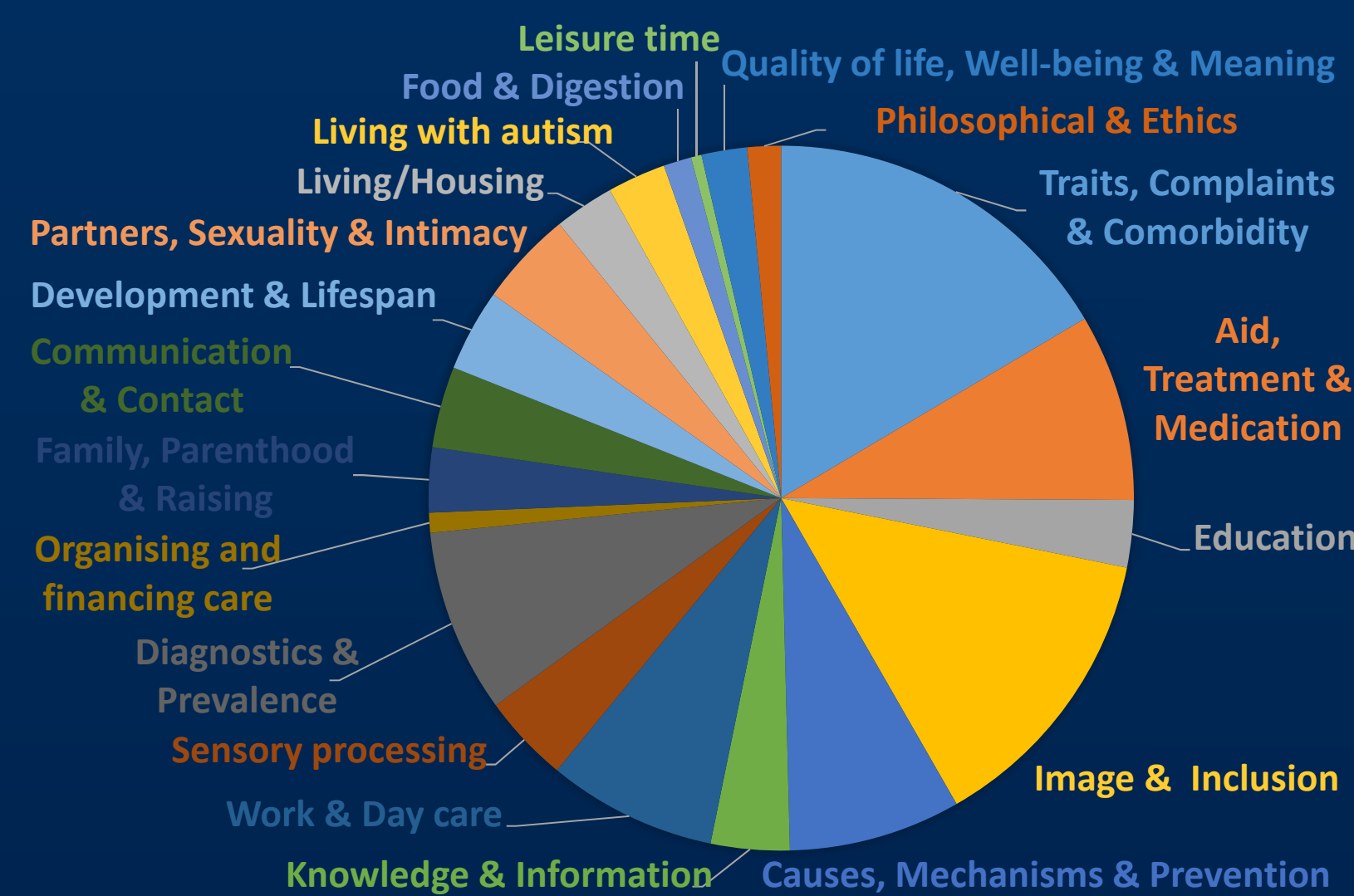
- “ What kind of help does the whole family of a child with autism need; how to involve the whole family in treatment and support?
- “ How to realise curricula at all schools based on diversity. Now it's all based on averages.
- “ What will parents who have ASD help / support best?



Legal representatives
n=62
M/F/X 45/17/-

- “ Why are insights from scientific research used so scarcely and inconsistently in health care and support practices?
- “ Since 2018, municipalities have been allowed to determine their own policies concerning health care and support to children and youth ("Jeugdwet"). To what extent are children with autism reflected in their policies?

20 themes

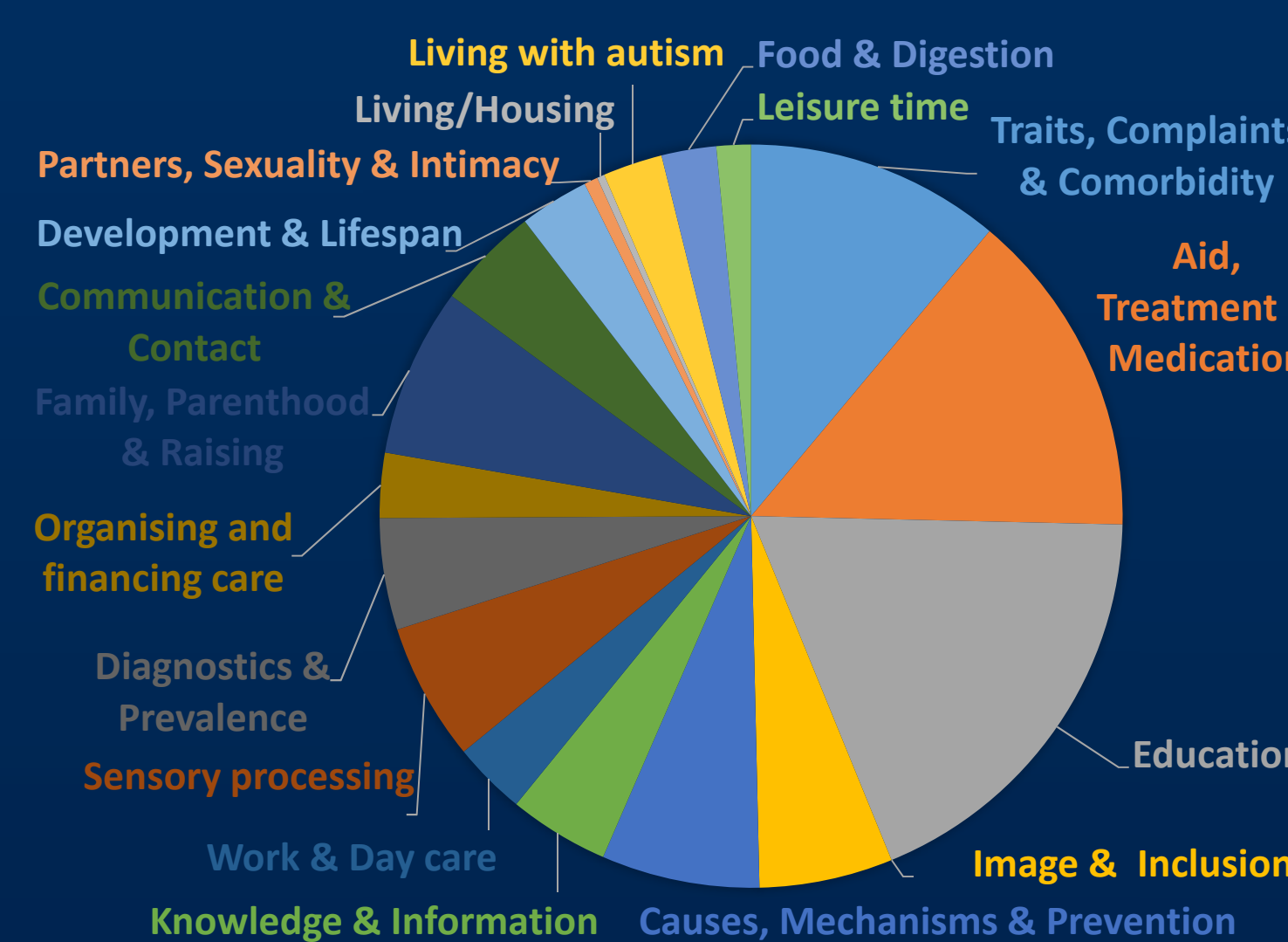


Autistic Adults

Autistic adults specifically call for: *Image of autism & societal inclusion (IS)* and *Diagnostics & Prevalence*. *IS* includes research about 'invisibility'. *Diagnostics* research should focus on women, high IQ and ages 50 and up. Autistic adults are the only group that mention research needs relating to quality of life or philosophy and ethics.

Top 5:

- 1 Traits, Complaints & Comorbidity
- 2 Image of autism & Societal inclusion
- 3 Support, Treatment & Medication
- 4 Diagnostics & Prevalence
- 5 Causes, Mechanisms & Prevention

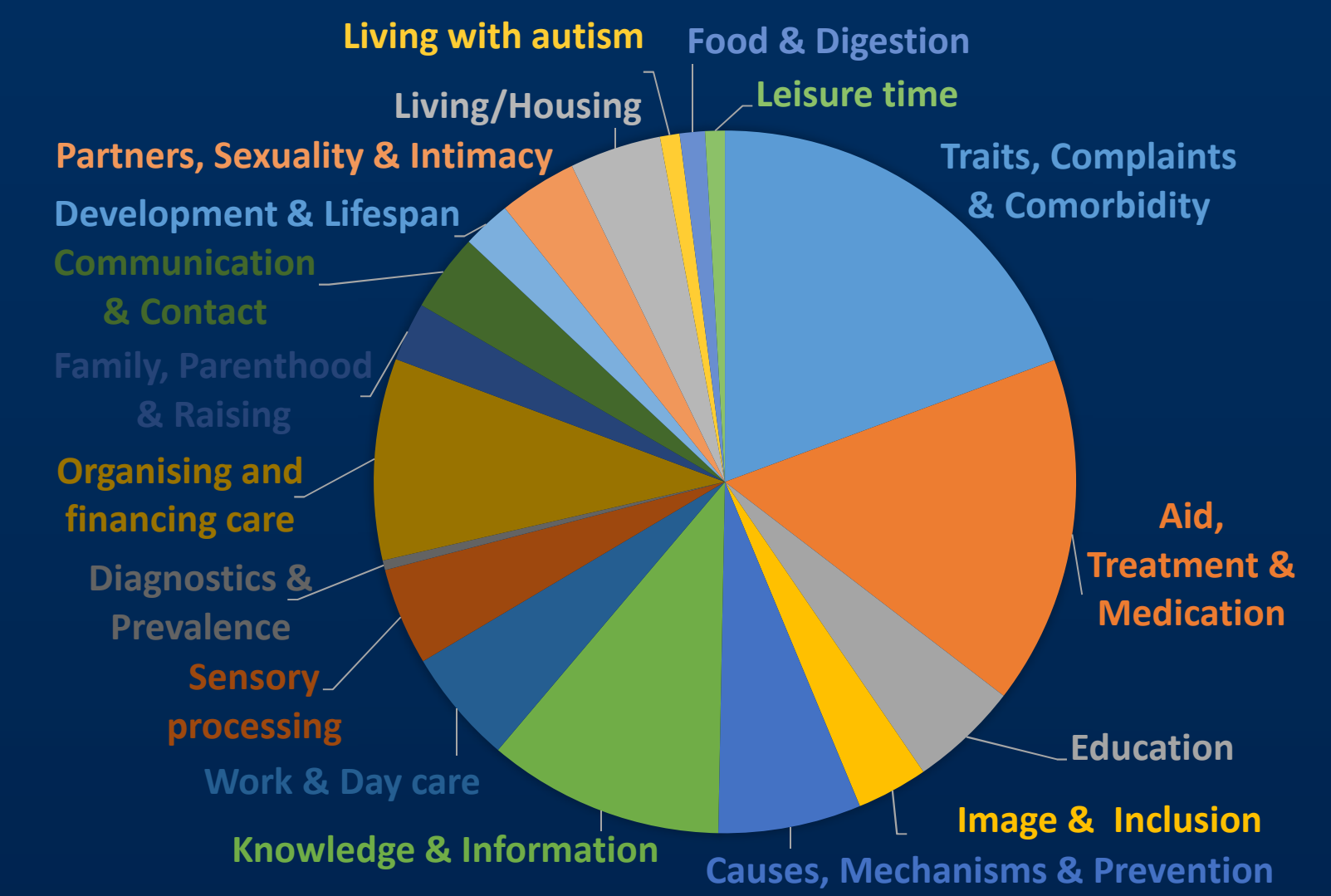


Parents

Parents specifically call for more research into *Education*, and into *Family, Parenthood & Child raising (FPC)*. *Education* includes raising the autism knowledge of educational professionals. *FPC* includes more research into being an autistic parent.

Top 5:

- 1 Education
- 2 Support, Treatment & Medication
- 3 Traits, Complaints & Comorbidity
- 4 Family, Parenthood & Child raising
- 5 Causes, Mechanisms & Prevention



Legal Representatives

Legal representatives specifically call for more research into *Knowledge & Information (KI)* and *Healthcare organisation & Finance (HOF)*. *KI* covers better dissemination of scientific knowledge towards practitioners, autistic people and their relatives. *HOF* is about the Dutch health care system and its effect on autism support and treatment, e.g. waiting lists, personal budgets.

Top 5:

- 1 Traits, Complaints & Comorbidity
- 2 Support Treatment & Medication
- 3 Knowledge & Information
- 4 Organising and Financing care
- 5 Causes, Mechanisms & Prevention

Conclusions

- We identified 20 research themes. Research needs according to the stakeholders are more diverse than is customary in autism research
- Many themes are multi-disciplinary
- There are clear differences between the three stakeholder groups
- All respondent groups ask for more research into *Traits, complaints and comorbidity*, *Support, treatment and medication* and *Causes, mechanisms and prevention*

Recommendations

- Invest in new areas of autism research. Autism research themes should become more diverse and include research questions about philosophy and ethics, knowledge dissemination, healthcare organisation & finance
- Establish a greater involvement of autistic people and their relatives in autism research, both in priority setting processes and in research in general



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Nederlandse Vereniging voor Autisme