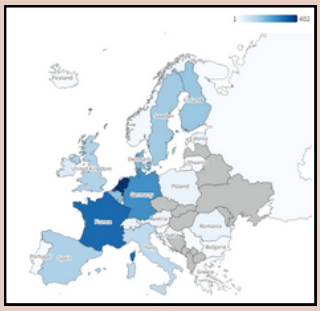
AUTISTIC PEOPLE'S PRIORITIES EUCAP SURVEY RESULTS

ABOUT THE SURVEY

Responses were collected during autumn 2021, through an online questionnaire available in 12 languages. 2441 responses were received from 31 countries. The main themes were:

- **research priorities**
- **treatments and support received and/or wanted;**
- **representation of autistic people in decision-making**

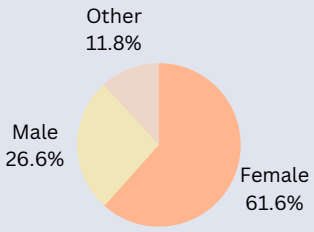


AGE

37.6 years

was the average age of the participants, ranging from 18 to 81.

GENDER



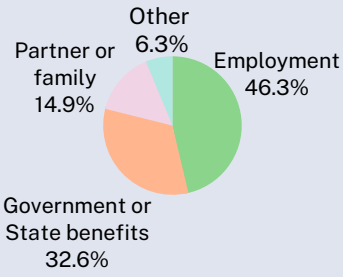
61.6% of the participants were female, 26.6% male, and 11.8% identified as 'other' (referred to later in this report as non-binary)

EDUCATION

17.3 years of schooling

This was the average number of years the participants had received education.

EMPLOYMENT



For 46.3% of participants, employment was their main source of income.

Participants had on average

4.94 more years of schooling

than the average in Europe (12.36 years)[1]

+

9.53% lower employment rate

than the average in Europe (55.83%)[2]

Data of 2021 for countries that participated in the survey - 1. Data by Global Data Lab (globaldatalab.org); 2. International Labour Organization (ilostat.ilo.org/data)

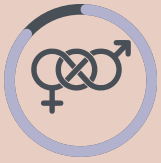
DIAGNOSIS

AGE OF DIAGNOSIS

32 years

was the average age for diagnosis, ranging from 1 to 19.

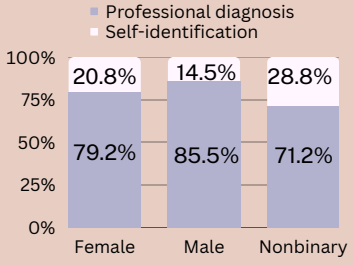
GENDER



87.5%

of women had not been diagnosed by the age of 18, compared with 72.4% of men and 79% of nonbinary people.

DIAGNOSIS VS SELF-IDENTIFICATION



Nonbinary people were most often self-identified, especially the younger ones.

For more information on the survey, visit https://eucap.eu/eucap-2021-survey

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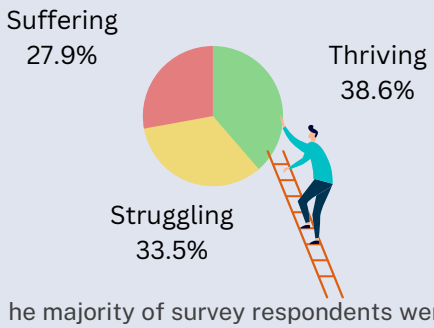
AUTISTIC PEOPLE'S PRIORITIES IN AUTISM RESEARCH - RESULTS FROM THE EUCAP SURVEY

QUALITY OF LIFE

The “Cantril Ladder”, as adopted in the Gallup World Poll, was used to assess quality of life, by asking "Imagine an eleven-rung ladder where the bottom (0) represents the worst possible life for you ad the top (10) represents the best possible life for you. On which step of the ladder do you feel you personally stand at the present time."

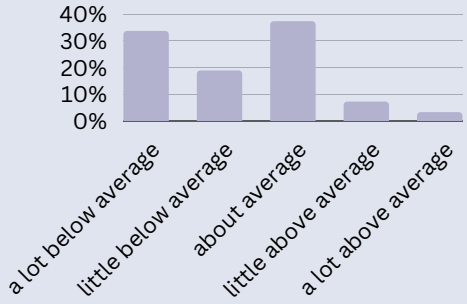
THRIVING, STRUGGLING OR SUFFERING?



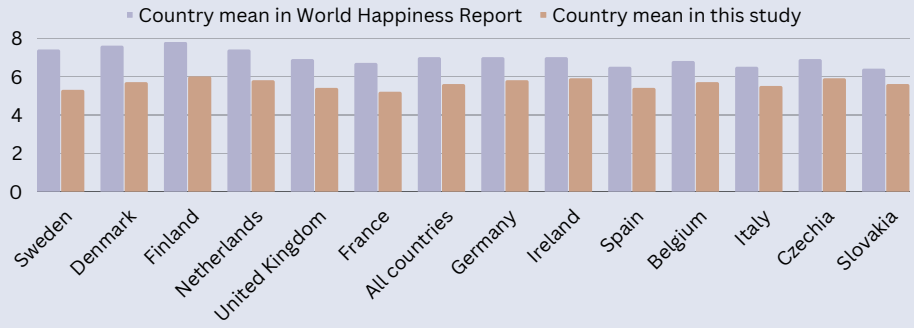
he majority of survey respondents were either struggling or suffering (61.4%)

COMPARISON OF INDIVIDUAL RESULTS WITH THEIR COUNTRY AVERAGE

When comparing the participants to their country average, most had a below average quality of life (52.4%).



COMPARISON OF COUNTRY RESULTS IN OUR STUDY AND WORLD HAPPINESS REPORT AVERAGE



The greatest differences between the World Happiness Report country values and our participant values were seen in Sweden, followed by Denmark and Finland.

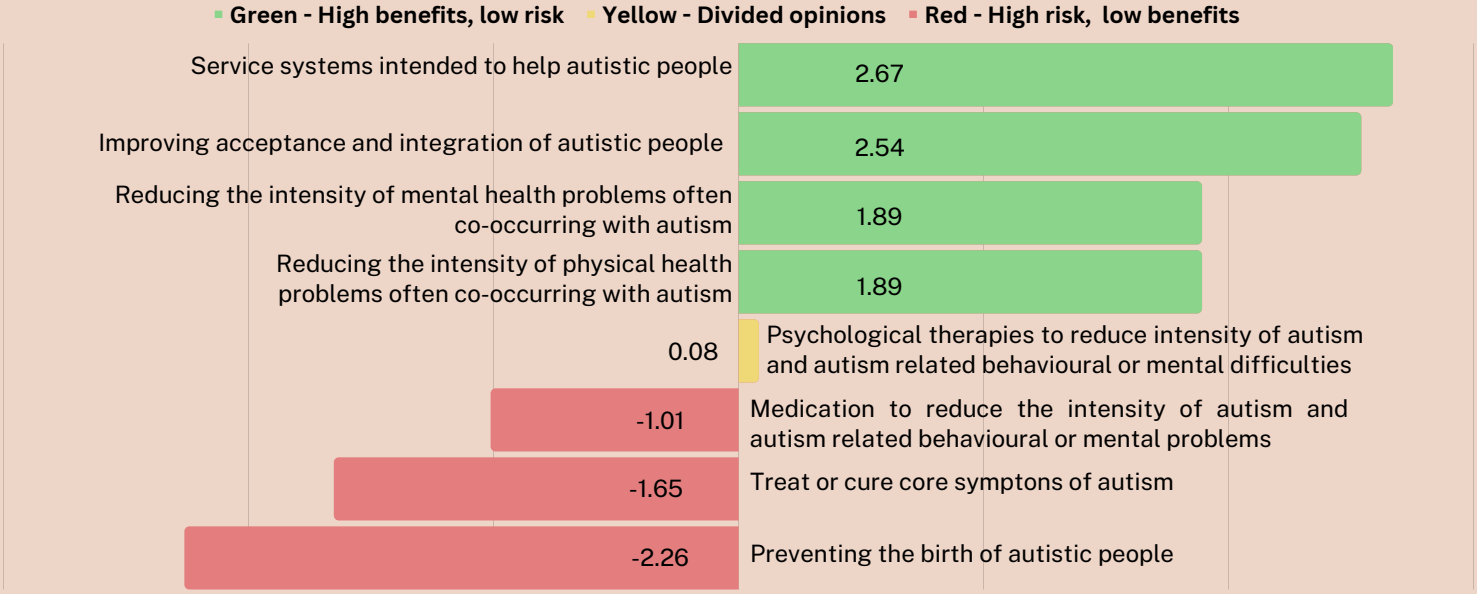
Results must be interpreted with caution, as the demographics of participants varied by country.

Helliwell, J. F., Layard, R., Sachs, J. D., De Neve, J.-E., Aknin, L. B., & Wang, S. (Eds.). (2023). World Happiness Report 2023. New York: Sustainable Development Solutions Network.

RESEARCH

EXPECTED RISKS AND BENEFITS OF DIFFERENT TYPES OF RESEARCH

The participants' opinions were asked on six different types of research, indicating an expected risk of undesirable effects and expected benefits. The perceived net benefit was calculacted by substracting the mean of expected risks from the mean of expected benefits.



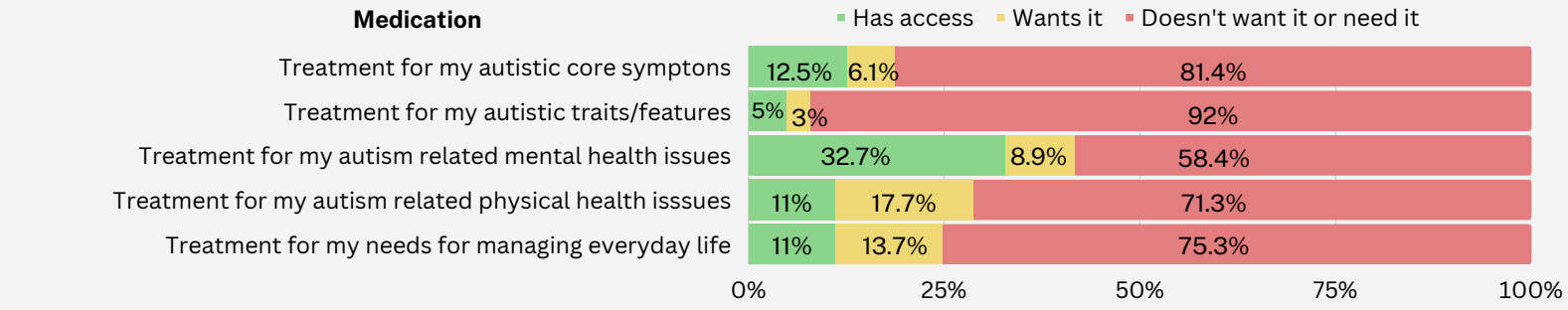
The respondents did not value (medical) research on the causes of autism or treatments for autism. They preferred research to promote acceptance and inclusion, and to build support systems.

There was a high level of agreement among respondents, except on the topic of psychological therapies. The results suggest that perceptions may vary between countries, with the most critical views in the United Kingdom, Ireland and France. Czechia, the Netherlands and Belgium appeared to have the most positive views.

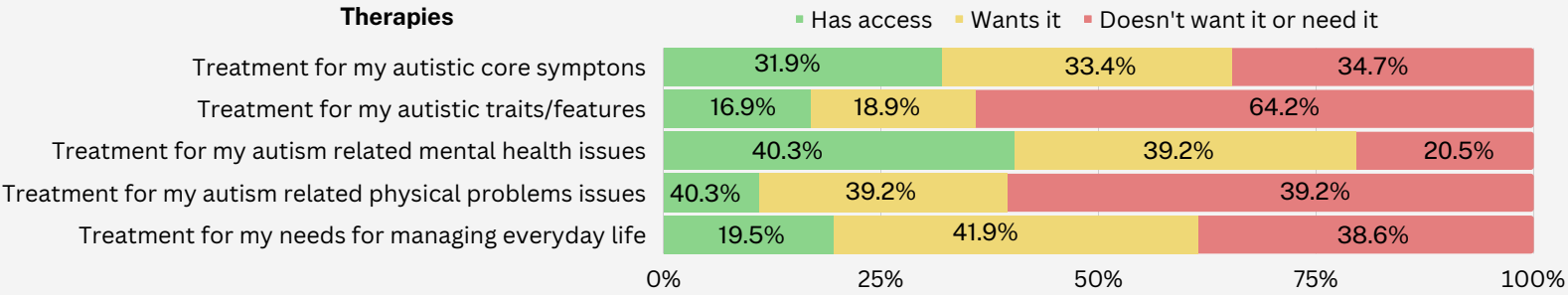
AUTISTIC PEOPLE'S PRIORITIES IN AUTISM RESEARCH - RESULTS FROM THE EUCAP SURVEY

WHAT TYPE OF (MEDICAL) TREATMENT DO YOU HAVE OR WOULD LIKE TO HAVE

Medication



Therapies



MEDICATION

47.5%
of survey participants wanted some type of medication, but

51.3%
of those who wanted it did not have access to it

Medication for mental issues was the most commonly received or wanted, being available to 32.7%. Medication for physical issues was most commonly wanted but not received (17.7%), while medication for autistic traits/features was the least wanted (7.9%).

THERAPIES

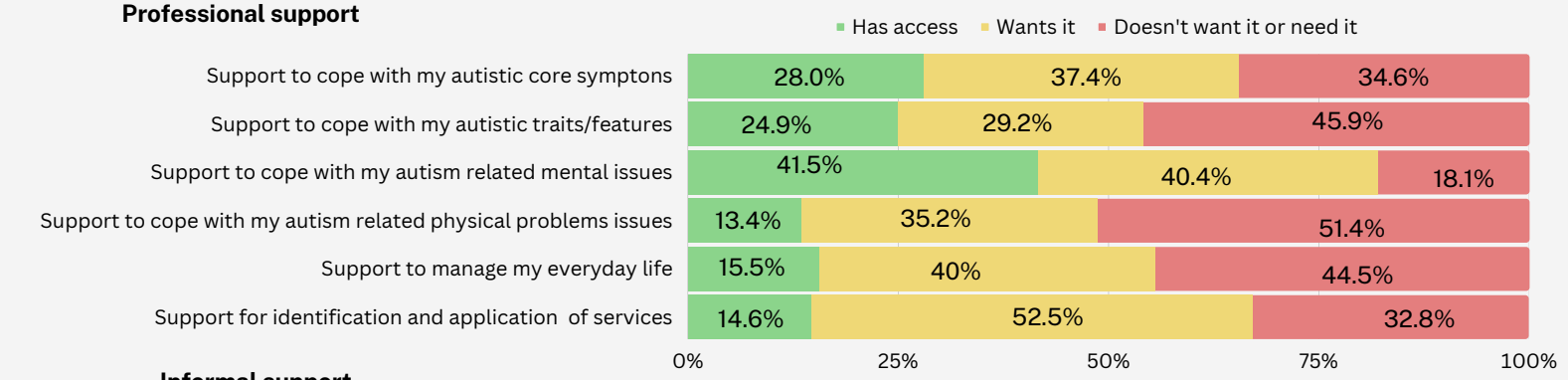
72.9%
of survey participants wanted access to therapy, but

71.3%
of those who wanted it did not have access to it

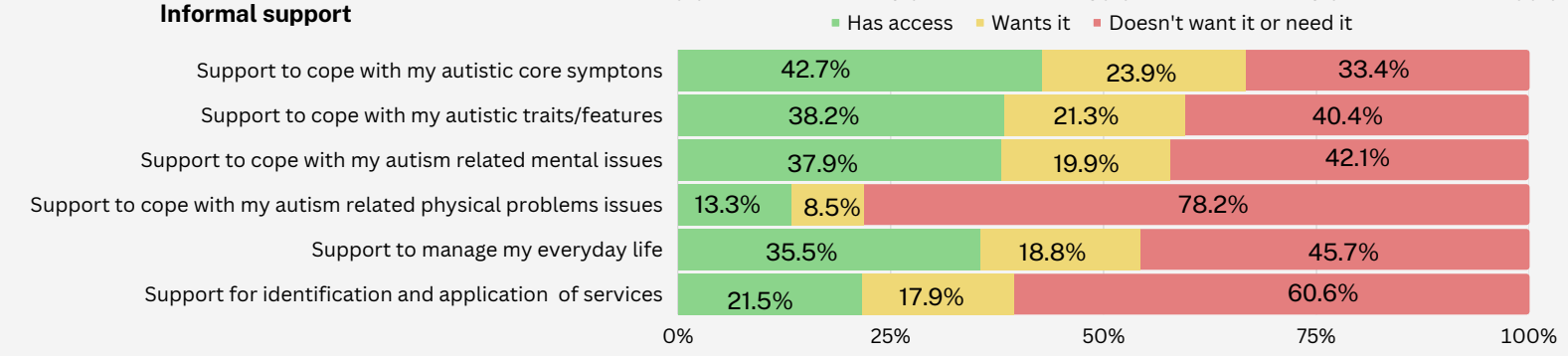
Therapy for mental health issues was the most commonly received or wanted, being available to 40.3%. Therapy for needs for managing everyday life was most commonly wanted bu not received (41.9%), while therapy for autistic traits/features the least wanted (35.8%)..

WHAT TYPE OF SUPPORT DO YOU HAVE OR WOULD LIKE TO HAVE ACCESS TO

Professional support



Informal support



PROFESSIONAL SUPPORT

94.4%
of respondents wanted access to professional support, but

43.2%
of those who wanted it did not have access to it.

Professional support for mental issues was the most commonly rceived or wanted (81.9%), and the most frequently available (41.5%), while professional support for physical problems was the least wanted (13.4%). Professional support for finding services and applying for them was most frequently wanted but not received (52.5%).

INFORMAL SUPPORT

84.4%
of respondents wanted informal support, but

28.2%
of those who wanted it did not have access to it

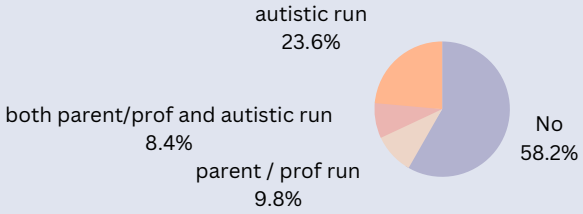
Informal support for autistic core traits was the most commonly received or wanted (66.6%), and the most frequently available (42.7%), Informal support for autistic core traits was most frequently wanted but not received (23.9%), while informal support for physical problems was the least wanted (21.8%).

AUTISTIC PEOPLE'S PRIORITIES IN REPRESENTATION - RESULTS FROM THE EUCAP SURVEY

MEMBERSHIP OF ORGANISATIONS

Participants were asked if they were members of an autism advocacy, self-help or social organisation.

58.2 % of respondents were not members of any such organisaton.
Independently of gender, age or diagnostic status, the most common membership was with autistic-led organisations.
Membership was more common among older participants with professional diagnosis.

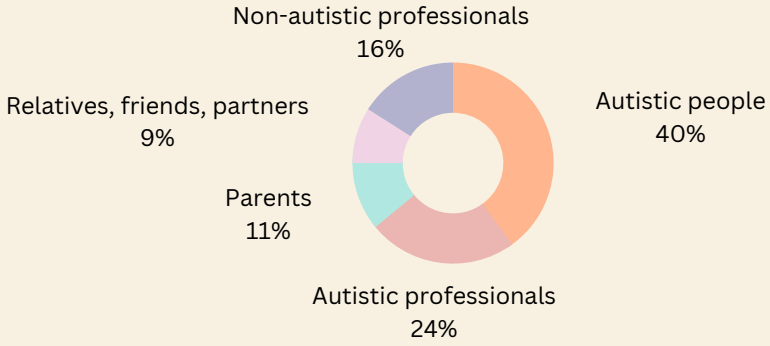


REPRESENTATION

Participants were asked about an ideal imaginary committee that would represent autistic people in all decision-making concerning autism policies, research, support and campaigning.

64% was considered the ideal proportion of autistic people, with 36% non-autistic

Participants wanted autistic people to be primarily represented by other autistic people. Parents, partners or non-autistic professionals were seen as ideally having a smaller role when making decisions about issues concerning autistic people.



FIRST THREE SUBJECTS THAT THIS COMMITTEE WORKS/DECIDES ON

The participants were asked about the first three topics that the committee they chose should work on.

This was an open ended questions with 1444 respondents. The words used most frequently in the responses are shown below.

RECOMMENDATIONS

01 Research and data collection on autistic needs and priorities

02 Acceptance, community involvement and social inclusion

03 Improving support, diagnostic and care services

04 Creating accessibility and reasonable adaptations in public and private spaces, including in communication (AAC)

05 Autistic advocacy, political participation and improved access to rights

06 Awareness, information and educational programs in society about autism

07 Fighting violence and human rights violations, including banning or awareness of harmful interventions

08 Changing research topics or refocusing on social issues and understanding autistic needs

09 Improving economic and financial support

10 Education and inclusion in schools

11 Employment and inclusion in the workplace

12 Fighting discrimination, ableism, violence and human rights violations

13 Housing and independent living

14 Improving quality of life and well-being