



POINTS OF
CONNECTION



QUALITY OF LIFE

RESEARCH AS PART OF POINTS OF CONNECTION PROJECT

About Points of Connection

Points of Connection is a KA2 project funded by Erasmus+. The main objective of 'Points of Connection' is to foster better inclusion of autistic young people in our communities.

This has been done through:

1. Creation of an online Quality of Life inclusive measure and gathering of data on the Quality of Life of autistic young people in different countries.
2. Supporting in making services and public/private sectors more accessible for persons with autism in the different project countries
3. Finding points of connection to explore different platforms by autistic young people and neurotypical peers.

The project has a group of autistic young people from 5 partner countries who worked with the management team throughout the whole project.

Points of Connection: Autism in the Community is a project funded by Erasmus+. The coordinator is Prisms Malta, leading a consortium which includes Fundacja Imago based in Poland, Autisme-Europe based in Belgium, CRPD Malta, PLOES based in Greece, Federacio Catalana d'Autisme based in Spain and Associacao Portuguesa Voz do Autista.

Please follow the website for more information: <https://pointsofconnection.prismsmalta.com/>



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QUALITY OF LIFE MEASURE

1. Measuring QOL (domains and indicators)

Initially, the assessment of QOL was used in very different situations and approached from multiple perspectives, which resulted in over 1,243 measures by the mid-1990s. (C. Hughes et al, 1995). Nowadays current measurement of QOL is simpler as it can be characterized by the following:

- a. The multidimensional nature of QOL which involves core domains and indicators;
- b. The use of pluralism which involves the use of subjective and objective measures;
- c. A system that includes the various environments impacting people at the micro-, meso- and macro-systems levels; and
- d. The enhanced inclusion of persons with ID in the design and implementation processes (M. A. Verdugo et al, 2005) (G. S. Bonham et al, 2004).

Through a validation from a series of cross-cultural studies, the QOL framework consists of eight important domains (R. L. Schalock et al., 2005; C. Jenaro et al., 2005; R. L. Schalock et al., 2002; M. Wang et al., 2010). The eight domains are personal development and self-determination (these two show the level of independence), interpersonal relations, social inclusion, rights (these reflect the person's social participation) and emotional wellbeing, physical wellbeing and material wellbeing (R. L. Schalock et al., 2005; C. Jenaro et al., 2005; R. L. Schalock et al., 2002; M. Wang et al., 2010). The literature regarding QOL does

not speak about a hierarchy between the domains nor does it show cause and effect relations among them (G. S. Bonham, 2004).

The eight domains can be too broad when measuring if a person has a good QOL and can be misleading when seeking to investigate and differentiating the actual level of QOL. A very good analysis by Schalock and Verdugo published in 2002 facilitated this problem after studying in-depth 897 articles, and coming up with the three most common indicators for each of the eight core QOL domains.

| QOL Domains | Indicators |
|------------------------------------|--|
| 01. EMOTIONAL WELL-BEING | <ul style="list-style-type: none"> Contentment (satisfaction, moods, enjoyment) Self-concept (identify, self-worth, self-esteem) Lack of stress (predictability, control) |
| 02. INTERPERSONAL RELATIONS | <ul style="list-style-type: none"> Interactions (social networks, social contacts) Relationships (family, friends, peers) Supports (emotional, physical, financial, feedback) |
| 03. MATERIAL WELL-BEING | <ul style="list-style-type: none"> Financial status (income, benefits) Employment (work status, work environment) Housing (type of residence, ownership) |
| 04. PERSONAL DEVELOPMENT | <ul style="list-style-type: none"> Education (achievements, status) Personal competence (cognitive, social, practical) Performance (success, achievement, productivity) |
| 05. PHYSICAL WELL-BEING | <ul style="list-style-type: none"> Health (functioning, symptoms, fitness, nutrition) Activities of daily living (self-care skills, mobility) Leisure (recreation, hobbies) |
| 06. SELF-DETERMINATION | <ul style="list-style-type: none"> Autonomy/personal control (independence) Goals and personal values (desires, expectations) Choices (opportunities, options, preferences) |
| 07. SOCIAL INCLUSION | <ul style="list-style-type: none"> Community integration and participation Community roles (contributor, volunteer) Social supports (support network, services) |
| 08. RIGHTS | <ul style="list-style-type: none"> Human (respect, dignity, equality) Legal (citizenship, access, due process) |

(Schalock & Verdugo, 2002)

2. QOL and intellectual disability

With all the difficulties and challenges faced by persons with ID, it is a common belief among many that the persons with ID cannot achieve a decent QOL (Schalock & Verdugo 2002). Saying this, QOL is a very important concept as it is related to disability reforms, public policy and action strategies that need to be employed at the all the levels of society (Schalock, R. L., 2004). Keeping these in mind will help with the understanding of why QOL is such an important matter, especially for persons with ID.

First of all, there is currently an increased concern for the social and psychological dynamics of general well-being, autonomy, social support and social integration, confidence, aspirations and values that have to do with family, job and life in general (Schalock, R. L., 2004). Secondly, disability especially ID is a condition that affects people's ability to make self-determined choices. Therefore, even living an ordinary life will require specific support such as specialized training, guidance or specially designed environmental or social arrangements: this is where the concept of QOL becomes central in the assistance that needs to be given (Schalock, R. L., 2004). Lastly, people with ID often experience challenges when it comes to participation in society and are in a greater risk of exclusion from opportunities that are normally available to others (Schalock, R. L., 2004). "Therefore the concept of QOL is beginning to impact social policy and serve as the conceptual basis for developing environments that allow access for all persons to people, places, and resources" (Schalock, R. L., 2004, 2).

3. Simplifying and making the QOL more accessible

As an objective for this research, a team made of professionals from PLOES Greece, Prisms Malta and CRPD Malta met various times to discuss on ways how to make the QOL measure more accessible for persons with disabilities – in order to reach the people we were targeting to reach.

There are different ways of measuring the QOL of a person. However, for this reason, we used an online platform which we built for this project <https://pointsofconnection.prismsmalta.com/>

From the table with the indicators and the domains – a question was created for each of the indicator in order to reflect as appropriately as possible the answer. These are presented in the table below. The questions have been reviewed by all the consortium and by the autistic young people in the working groups in the respective countries.



QUESTIONS LINKED TO THE DIFFERENT DOMAINS

| QOL Domains | Indicators | Questions |
|---|--|--|
| <p>01. EMOTIONAL WELL-BEING</p> | <ul style="list-style-type: none"> ● Contentment (satisfaction, moods, enjoyment) ● Self-concept (identify, self-worth, self-esteem) ● Lack of stress (predictability, control) | <ul style="list-style-type: none"> ● In what level do you think you are happy? ● How much do you value yourself as an individual? (open comments about bullying) ● How often you think you are stress free and able to manage stress? |
| <p>02. INTERPERSONAL RELATIONS</p> <p>Building connections, and understanding each other in relationships, and finding support in times of need.</p> | <ul style="list-style-type: none"> ● Relationships (family, friends, peers) ● Interactions (social networks, social contacts) ● Supports (emotional, physical, financial, feedback) | <ul style="list-style-type: none"> ● How is your relationship with your family? ● How is your relationship with your friends? ● Do you find adequate support for you in times of need? |

03. MATERIAL WELL-BEING

Having enough resources to live comfortably and to meet your needs, like food, shelter and clothing.

- Financial status (income, benefits)
- Employment (work status, work environment)
- Housing (type of residence, ownership)
- Do you have enough income to meet your basic needs?
- What is your level of satisfaction with education/employment?
- Think about your living environment and the people who live in it. Are you satisfied with the place you live in?

04. PERSONAL DEVELOPMENT

- Education (achievements, status)
- Personal competence (cognitive, social, practical)
- Performance (success, achievement, productivity)
- How satisfied were you with your educational experience?
- In what level you think you are competent in various areas of life?
- In what level are you improving yourself and how satisfied are you with your progress?

05. PHYSICAL WELL-BEING

- Health (functioning, symptoms, fitness, nutrition)
- Activities of daily living (self-care skills, mobility)
- Leisure (recreation, hobbies)
- How healthy do you think you are based on your sleeping patterns, eating habits and exercise?
- How much do you think you can care for yourself and have access to healthcare if needed?
- How satisfied are you with the leisure activities in your life?

06. SELF-DETERMINATION

Having the choice to set your own goals, making your own life decisions, self-advocating and working to reach your goals. It is about taking action in your life to get the things you want and need.

- Autonomy/personal control (independence)
- Goals and personal values (desires, expectations)
- Choices (opportunities, options, preferences)
- How much do you feel you have control over your decisions e.g. what and when to eat, where to go, etc?
- Do you feel that you can set your own goals?
- How much do you feel supported in carrying out decisions?



07. **SOCIAL INCLUSION**

Feeling that you are part of the community/society around you, feeling that you belong and feeling supported.

- Community integration and participation
- Community roles (contributor, volunteer)
- Social supports (support network, services)
- Do you feel that you are part of your community?
- What is your level of participation in the community?
- Do you feel supported in your community?

08. **RIGHTS**

Human rights are the basic rights and freedoms that we all have. For example, you have the right to be safe and to be treated fairly. You also have the right to make choices, and take part in your community.

- Human (respect, dignity, equality)
- Legal (citizenship, access, due process)
- Are you satisfied with how your human rights are respected/valued?
- How much do you feel you know about what human rights are? (Rate your knowledge on human rights)
- Do you know what you need to do if your human rights are not respected/valued?





RESEARCH FINDINGS

General Overview

The QOL measure was conducted across five partner countries through the website, gathering data from 199 participants. The results from the autistic young people are as follows:

| Country | Participants | Average Age | Average QOL Score (%) |
|----------|--------------|-------------|-----------------------|
| MALTA | 40 | 26 | 71.63 |
| GREECE | 18 | 26 | 76.3 |
| PORTUGAL | 62 | 30 | 58.9 |
| SPAIN | 52 | 25 | 62.2 |
| POLAND | 23 | 31 | 65.8 |
| OVERALL | 199 | 28 | 64.4 |



MALTA'S QUALITY OF LIFE RESULTS

The Quality of Life assessment in Malta showed that participants generally felt a strong sense of social connection and stability. The highest-rated domain was interpersonal relations, with an average score of 4.00. This suggests that individuals in Malta have well-established personal networks and receive significant support from family, friends, and their communities. Additionally, material well-being received a relatively high score of 3.74, indicating that many participants have adequate financial resources and a stable economic situation.

Social inclusion was another notable strength, scoring 3.65. This finding reflects a sense of belonging within the community, though some participants may still encounter barriers to full participation. However, the results also highlighted areas for improvement. The lowest-scoring domain was rights, at 3.14, which suggests that participants may experience difficulties in advocating for their needs or accessing legal protections. Emotional well-being also presented some challenges, with a score of 3.45, implying that stress and mental health concerns may be prevalent. Finally, self-determination, with a score of 3.56, indicates that while individuals feel some autonomy in their decisions, additional support may be needed to enhance personal empowerment and independence.

Overall, the findings from Malta suggest that while participants experience strong social ties and financial stability, there is room for improvement in ensuring equal rights, mental well-being, and personal agency.

Participants in Malta reported a strong sense of interpersonal relations, which was the highest-scoring area with an average rating of 4.00. This suggests that individuals feel connected and supported by those around them. Material well-being was also a notable strength, scoring 3.74, indicating that participants have access to sufficient financial resources and stability. Social inclusion was another relatively strong area, with a score of 3.65, showing that many individuals feel integrated into their communities. However, there were some challenges reported, particularly in the domain of rights, which scored the lowest at 3.14. Emotional well-being, with a score of 3.45, was another area of concern, suggesting that some participants may struggle with stress or mental health challenges. Self-determination scored 3.56, indicating that while participants feel some level of control over their lives, improvements could be made in supporting personal autonomy and decision-making.

Quality of Life Measure in Malta

Data from 40 participants

Average age:

26 years

Average percentage of QOL:

71.63%

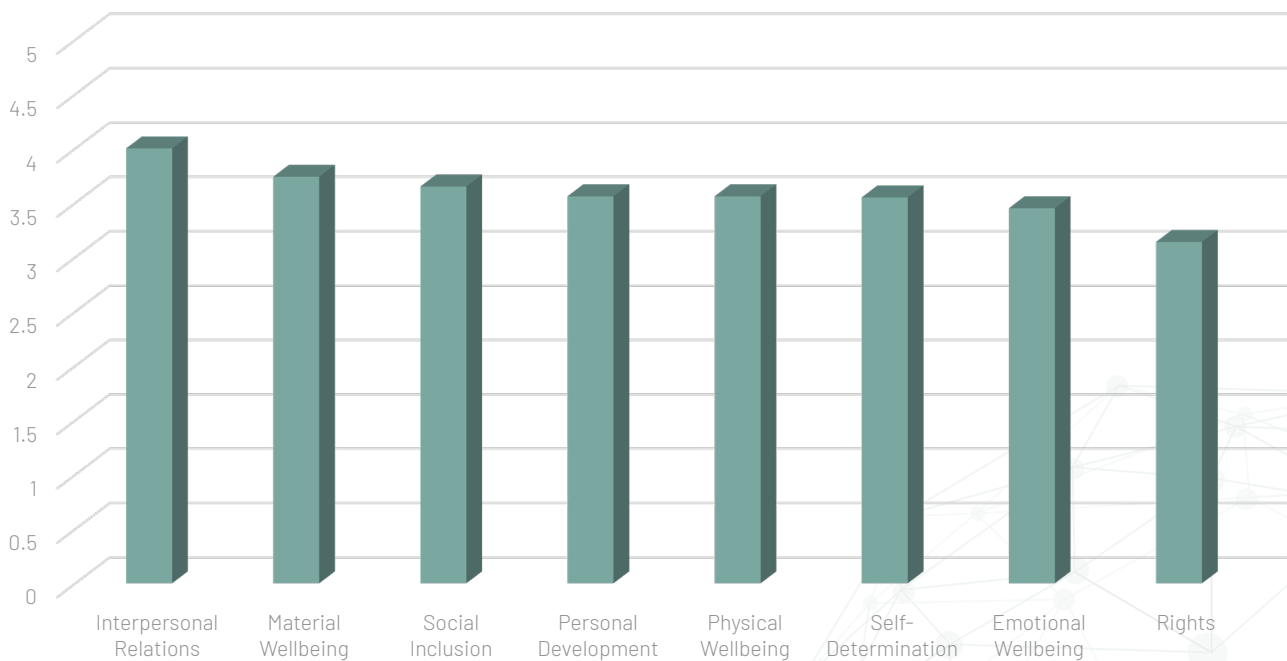


Figure: Quality of Life Measure in Malta



GREECE'S QUALITY OF LIFE RESULTS

The Quality of Life assessment in Greece demonstrated a strong sense of personal empowerment and social connectivity among participants. The highest-rated areas were self-determination and interpersonal relations, both scoring 4.16. These findings suggest that participants feel confident in making their own decisions and have meaningful social connections that provide support and encouragement. Material well-being was another well-performing domain, with a score of 4.07, indicating that many individuals experience financial stability and have access to essential resources.

Despite these strengths, certain challenges were identified. Social inclusion received the lowest score at 3.44, suggesting that while participants have strong personal relationships, they may still face difficulties fully integrating into broader societal structures. Emotional well-being was also an area of concern, scoring 3.52, which points to potential mental health struggles or emotional stress. Additionally, physical well-being received a score of 3.63, reflecting a moderate level of satisfaction with health and physical conditions but leaving room for improvement in areas such as healthcare accessibility and lifestyle support.

Quality of Life Measure in Greece

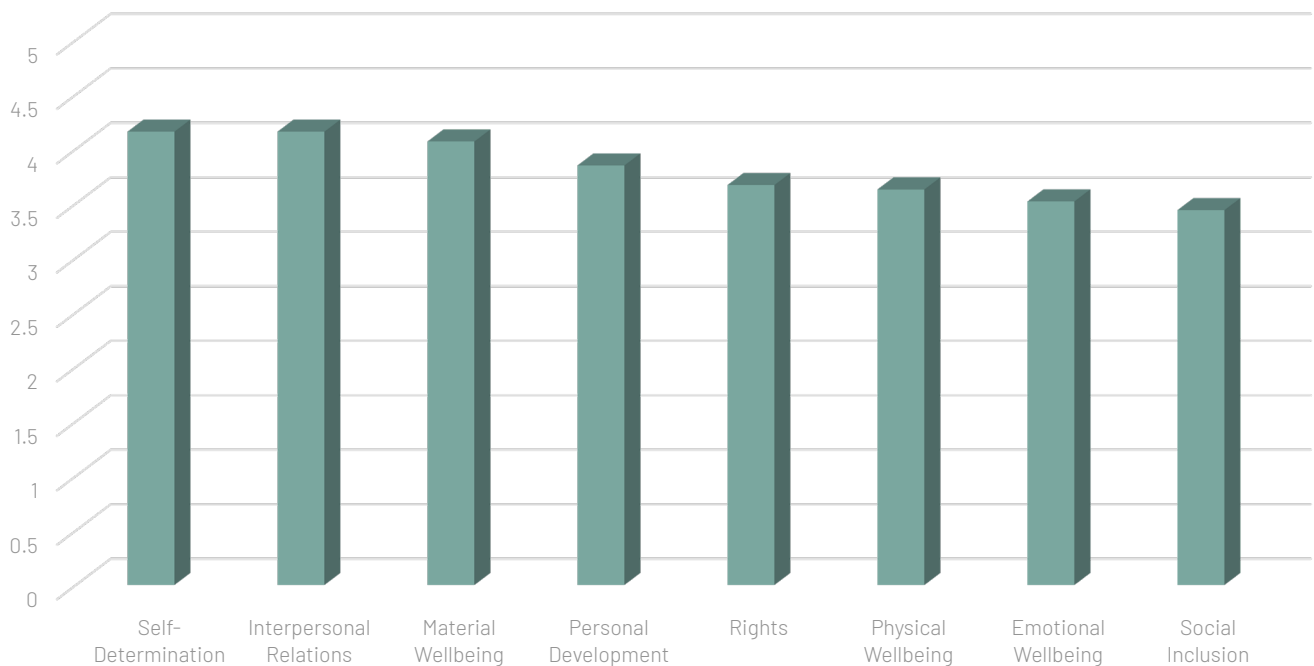
Data from 18 participants

Average age:

26 years

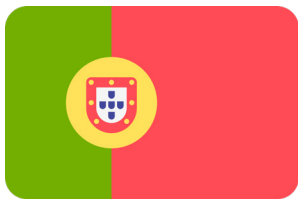
Average percentage of QOL:

76.3%



Overall, the findings from Greece highlight a population that feels socially and personally empowered, yet faces challenges in broader societal integration and emotional resilience. Addressing mental health support and creating more inclusive environments could significantly enhance the quality of life for participants in this region.

In Greece, self-determination and interpersonal relations were the highest-scoring areas, both receiving a score of 4.16. This indicates that participants feel empowered to make their own choices and experience strong social connections. Material well-being also performed well, with a score of 4.07, showing financial stability and access to resources. On the other hand, social inclusion was the lowest-scoring category, with a rating of 3.44, pointing to potential challenges in fully integrating into society. Emotional well-being was another area with room for improvement, scoring 3.52, while physical well-being received a score of 3.63, indicating a moderate level of satisfaction with health and physical conditions.



PORTUGAL'S QUALITY OF LIFE RESULTS

Participants in Portugal reported lower overall QOL scores compared to other countries, with an average rating of 58.9%. The highest-rated domain was self-determination, which received a score of 3.28. This suggests that while many individuals feel they have some level of control over their decisions and personal growth, there are still barriers limiting their full autonomy. Rights and material well-being followed closely, with scores of 3.13 and 3.07, indicating that while some participants felt financially stable and had access to necessary resources, others still faced economic challenges.

Interpersonal relations and personal development scored moderately at 3.03 and 3.00, showing that participants had some social support but might struggle with building meaningful connections or progressing in personal goals. However, significant challenges emerged in emotional well-being (2.67) and social inclusion (2.38), making them the lowest-scoring areas. These results indicate that many individuals in Portugal may experience difficulties in mental health and feel a lack of integration within their communities. Addressing these areas through enhanced community programs and mental health support could contribute to an overall improvement in their quality of life.

Quality of Life Measure in Portugal

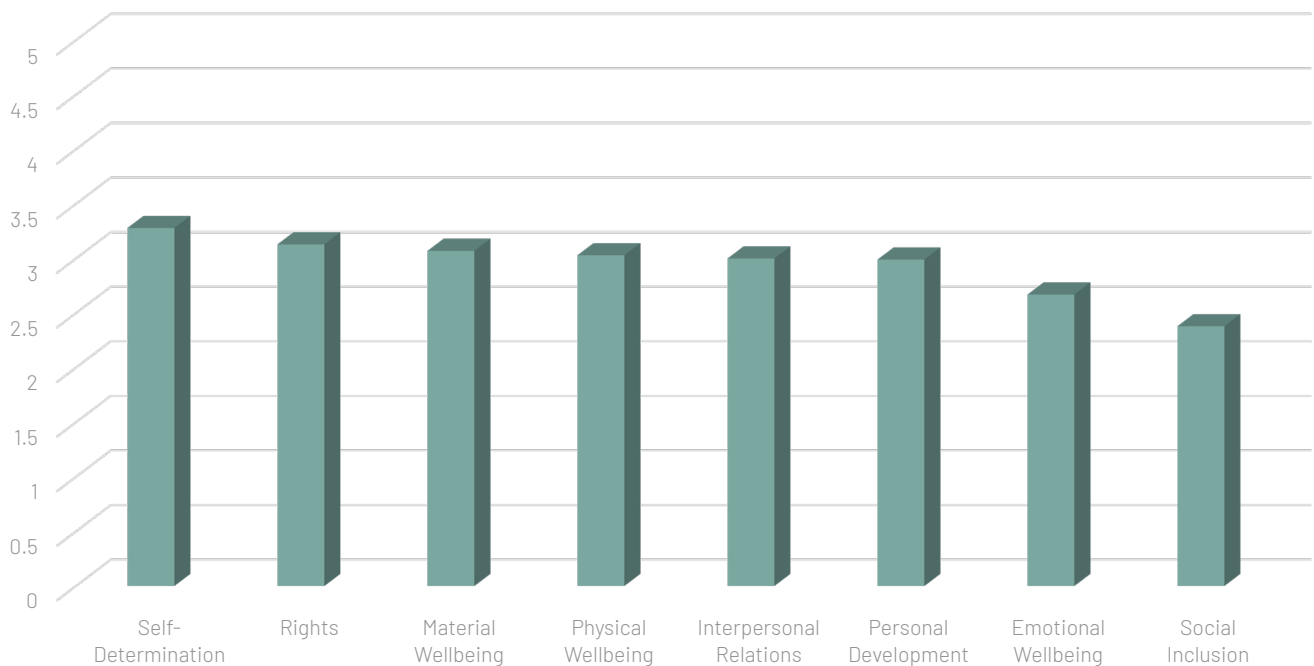
Data from 62 participants

Average age:

30 years

Average percentage of QOL:

58.9%



The Quality of Life assessment in Portugal showed a mixed picture. The highest-scoring area was self-determination, at 3.28, indicating that while many participants feel they have some control over their decisions, improvements could still be made. Rights and material well-being were also among the stronger domains, scoring 3.13 and 3.07



SPAIN'S QUALITY OF LIFE RESULT

The Quality of Life assessment in Spain revealed a moderately positive experience for participants, with an overall QOL score of 62.2%. The highest-rated domain was material well-being, which received a score of 3.48, indicating that many participants feel financially stable and have access to basic necessities. Interpersonal relations and self-determination followed closely, with scores of 3.38 and 3.33, respectively. These scores suggest that participants have meaningful social relationships and feel a reasonable level of autonomy in making personal decisions.

However, some areas presented notable challenges. The lowest-scoring category was social inclusion, at 2.78, reflecting difficulties in fully integrating into the community and accessing social support systems. Emotional well-being was another concern, scoring 2.81, which suggests that participants may experience stress, anxiety, or other mental health issues. Rights also scored relatively low at 2.86, highlighting potential difficulties in accessing legal protections or advocating for personal needs.

Overall, the results indicate that while participants in Spain benefit from stable financial conditions and strong social ties, they may struggle with broader societal integration, emotional resilience, and legal advocacy. Enhancing mental health resources and community participation opportunities could improve overall quality of life.

Quality of Life Measure in Spain

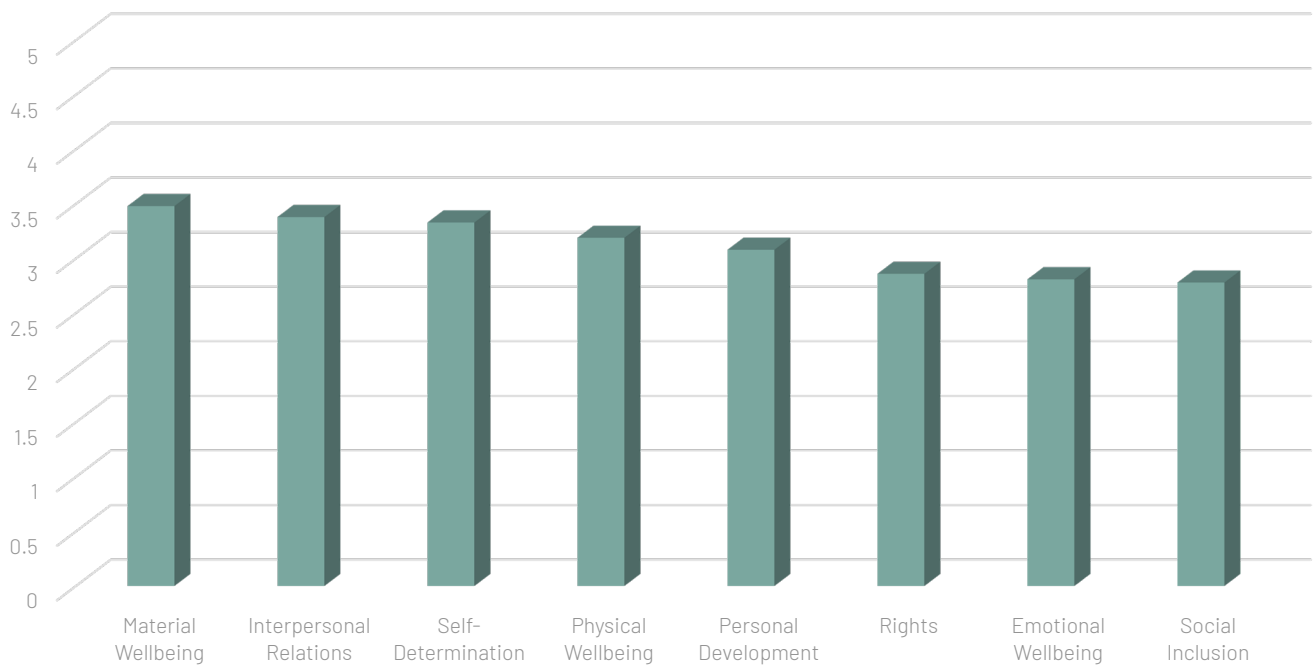
Data from 52 participants

Average age:

25 years

Average percentage of QOL:

62.2%





POLAND'S QUALITY OF LIFE RESULT

The Quality of Life assessment in Poland provided insights into both strengths and areas requiring improvement. With an overall QOL score of 65.8%, participants in Poland generally reported a moderate level of well-being. The highest-rated domain was material well-being, scoring 3.84, indicating that many participants feel financially secure and have access to essential resources. Physical well-being also scored relatively high at 3.49, suggesting a moderate satisfaction with health and physical conditions. Self-determination was another strength, with a score of 3.36, reflecting that many participants feel in control of their personal choices and decisions.

Despite these positive aspects, some domains received lower ratings. Social inclusion was the lowest-scoring area at 2.81, pointing to challenges in fully integrating into society and feeling a sense of belonging within the community. Emotional well-being and rights both scored 3.20, indicating that while participants may have some access to mental health support and legal rights, there is still room for improvement in these areas.

Overall, the results suggest that while participants in Poland experience financial stability and good physical health, they may face difficulties related to community engagement and emotional well-being. Strengthening social programs and providing greater mental health support could contribute to an improved quality of life for these individuals.

Quality of Life Measure in Spain

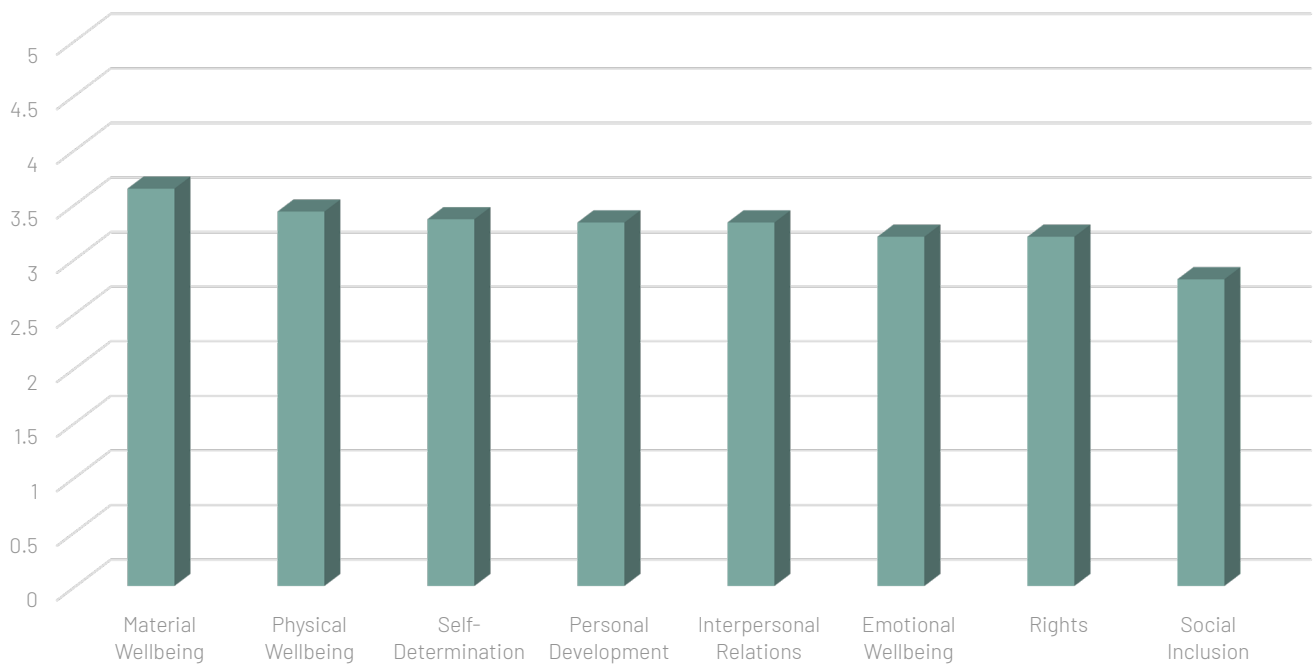
Data from 23 participants

Average age:

31 years

Average percentage of QOL:

65.8%





GENERAL OVERVIEW OF QUALITY OF LIFE FINDINGS

The Quality of Life (QOL) assessment conducted across five partner countries—Malta, Greece, Portugal, Spain, and Poland—provides a comprehensive understanding of the well-being of autistic young people in different European contexts. The study included 199 participants with an average age of 28, yielding an overall QOL score of 64.4%.

The findings highlight both strengths and challenges across various domains of life. Material well-being was the highest-rated domain in several countries, indicating a generally stable financial situation among participants. Interpersonal relations and self-determination were also areas of strength, especially in Greece and Malta, where participants expressed confidence in their personal decision-making and strong social connections.

However, certain challenges emerged across multiple locations. Social inclusion was consistently one of the lowest-scoring domains, particularly in Portugal and Spain, suggesting that many participants struggle to feel fully integrated into their communities. Emotional well-being was also identified as a concern, with low scores in several countries, reflecting issues related to stress, anxiety, and mental health support. The rights domain had relatively low scores as well, indicating potential barriers in accessing legal protections and advocacy opportunities.

Looking at the country-specific results, Malta and Greece reported the highest overall QOL scores, with participants in these countries feeling a strong sense of community, financial security, and personal agency. Poland had a moderate score, with strengths in material well-being and self-determination but challenges in social inclusion and emotional well-being. Spain and Portugal reported the lowest overall scores, particularly in areas related to mental health, social belonging, and access to supportive services.

These findings emphasize the need for targeted interventions, particularly in mental health support, community integration programs, and legal advocacy initiatives. Strengthening these areas can significantly improve the well-being of autistic young people across Europe, fostering a more inclusive and supportive society.

General Overview - All Partners

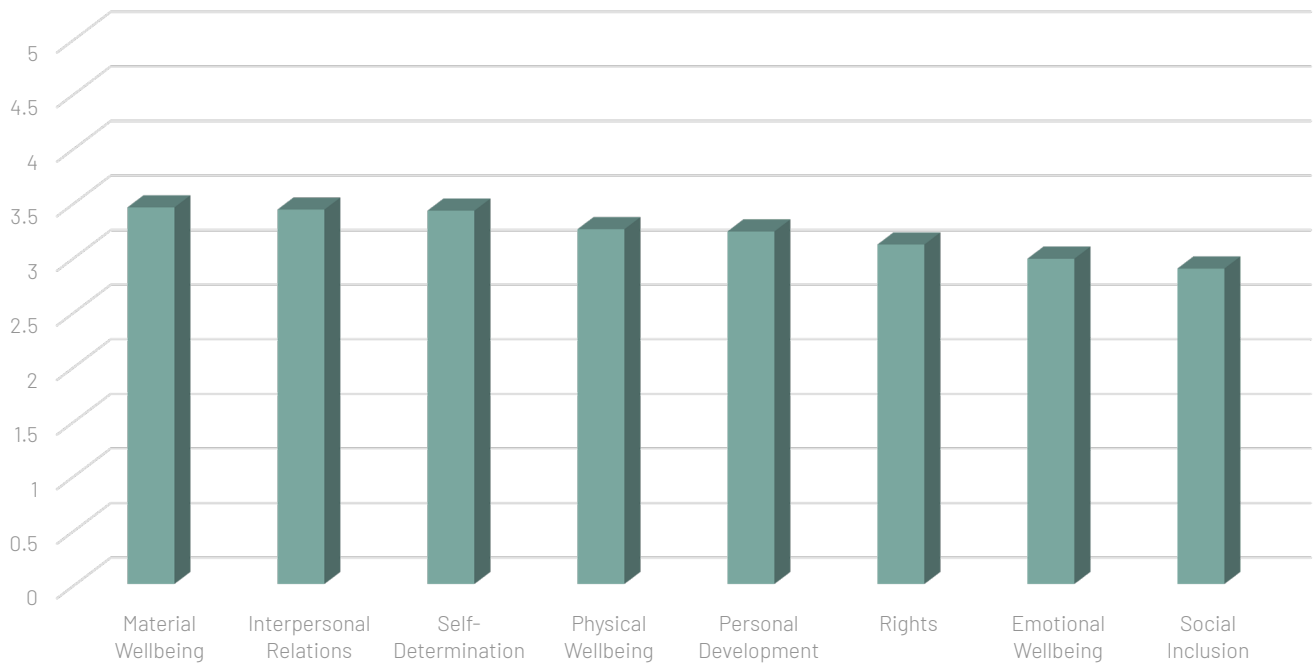
Data from 199 participants

Average age:

28 years

Average percentage of QOL:

64.4%





CONCLUSION

This research, based on responses from autistic young people across five European countries, provides valuable insights into their quality of life and the challenges they face. While material well-being and interpersonal relations emerged as key strengths, significant gaps were identified in social inclusion, emotional well-being, and access to rights and advocacy.

One of the most pressing concerns is the lack of community integration. Many participants reported feeling isolated or disconnected from broader society, particularly in Spain and Portugal, where social inclusion scored the lowest. Addressing this issue requires greater efforts in fostering inclusive environments, enhancing accessibility, and ensuring that autistic individuals are actively involved in their communities.

Another major gap identified was mental health support. Emotional well-being was consistently one of the lowest-rated domains across countries, indicating that many autistic young people struggle with stress, anxiety, and mental health-related challenges. Expanding mental health services, increasing awareness, and reducing stigma around mental health issues could be crucial steps in improving their overall well-being.

In addition, legal and advocacy barriers continue to hinder many autistic young people from fully exercising their rights. The relatively low scores in the rights domain highlight the difficulties faced in accessing necessary legal protections, employment rights, and advocacy resources. NGOs, policymakers, and service providers must work collaboratively to strengthen legal frameworks, provide clearer pathways to support, and ensure that autistic individuals have a voice in decisions affecting their lives.

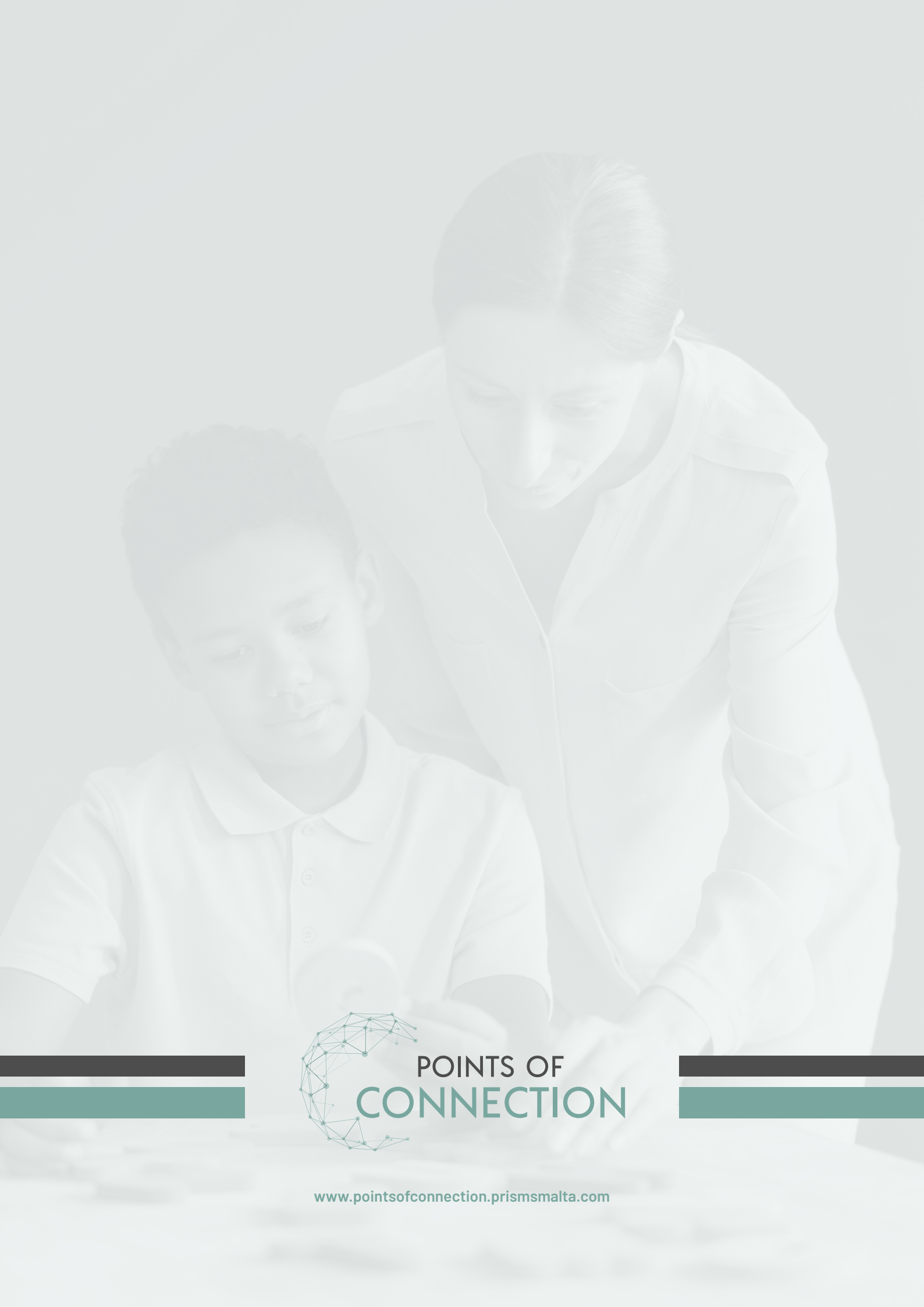


To improve the quality of life for autistic young people, NGOs and services must take an active role in bridging these gaps. This can be achieved through:

- Community-based programs that foster social inclusion and provide structured support for integration.
- Mental health initiatives tailored to the needs of autistic individuals, ensuring access to therapy, peer support, and crisis intervention.
- Stronger advocacy efforts that focus on policy change, legal protections, and creating more autism-friendly environments.

Overall, while autistic young people in these countries do experience a reasonable quality of life, there is still much room for improvement. By focusing on inclusion, mental health, and legal support, society can work towards ensuring that every autistic individual has the opportunity to thrive and participate fully in their communities.





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