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Redefining Quality of Life

Citizens with Intellectual Disabilities Voice their Lived Experiences and Perspectives

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Article

Perspectives of Adults with Intellectual Disabilities on Quality of Life: A Qualitative Study

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Intellectual Disabilities & Quality of Life

Life experiences of citizens with **Intellectual Disabilities** (IDs) are often characterized by:

- **social marginalization**
- **educational & professional exclusion**
- **pervasive stereotypes [1,2]**



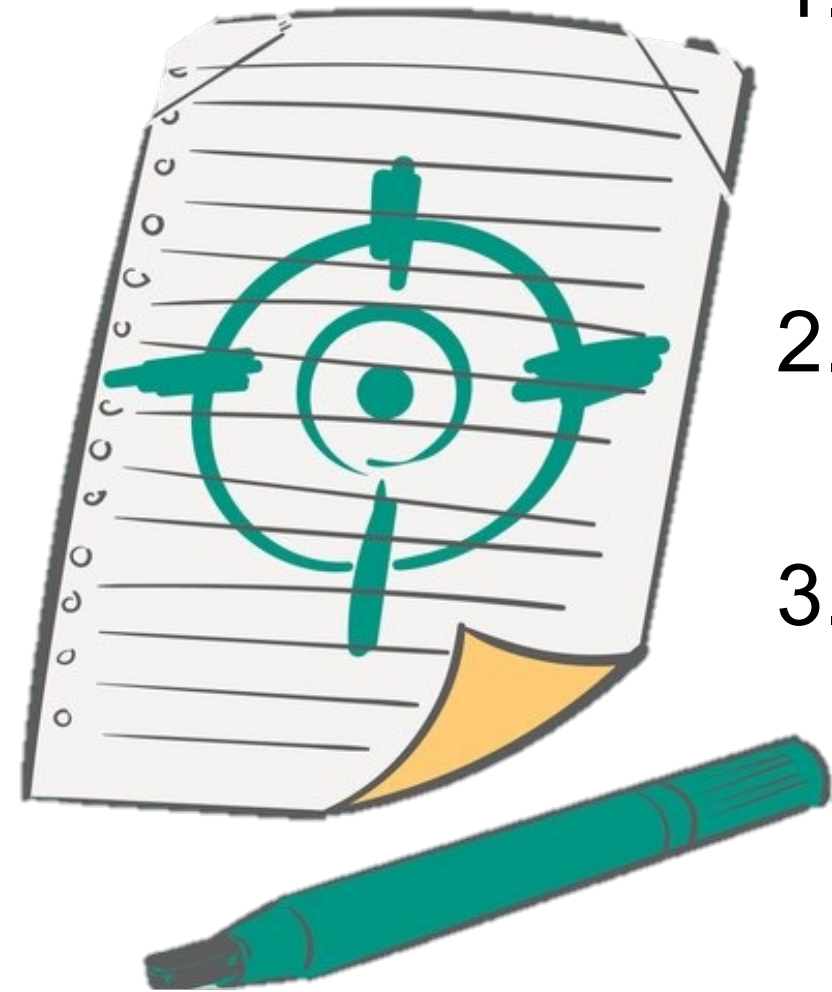
Most individuals with **IDs**:

- **live with their families**
- **participate in fewer social activities with friends**
- **have far fewer mutual friendships compared to their peers [3].**





Research Objectives



1. Explore the **occupations** of citizens with IDs and identify **factors restricting their access** and **active participation**.
2. Explore their **perceptions** about the **concept** and **meaning** of **QoL**.
3. Identify **factors influencing** their **QoL**, explore its **relationship** with **occupational participation**, and elicit their **perspectives** on its **improvement**.



Research Methodology



Qualitative
Research
Methodology

- ✓ Phenomenological approach
- ✓ Convenient Sampling
- ✓ Semi-structured interviews
 - **extensive insight** into participants' **beliefs** and **experiences**.



Inclusion
Criteria

- ✓ Diagnosis of **IDs**
- ✓ Attending a **Vocational Education Foundation*** (VEF)
- ✓ Ability of **verbal communication**
- ✓ **> 18** years of age



***Vocational Education
Foundation**

VEFs are specialized institutions designed to provide comprehensive **daily support** and **educational / therapeutic services** to adults with IDs in Greece.



Research Methodology

Occupational Justice

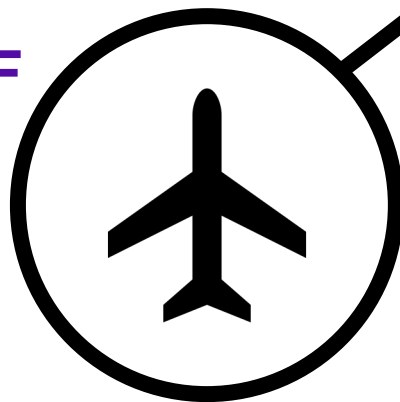


Pilot version tested with a female participant.

Pilot Interview



Revised Final Interview Guide



Pilot Interview Guide

- ✓ Refined question phrasing to **minimize unintentional guidance**.
- ✓ **Clarified abstract terms** like “**ποιότητα ζωής**” (**quality of life**), using participant language such as “**καλή ζωή**” (**good life**).
- ✓ Restructured interview format for a more **organic flow of topics**.

Interview Guide informed by **OJ [5]**, examining the relation between **occupational injustices / inequalities** and **QoL**.

Interview Guide Objectives:

- **activities** within the **VEF**
- **routines** and **interactions** in **home / leisure contexts**
- **perspectives** on **QoL**



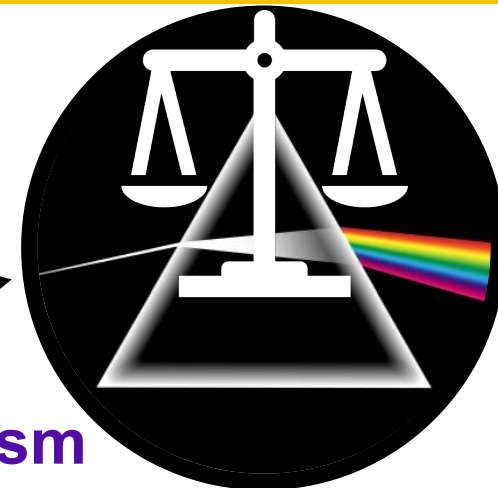
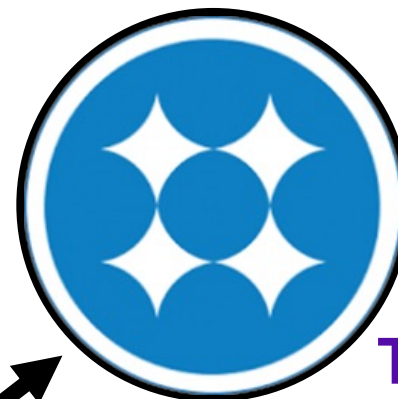
Research Methodology

Categories of Questions

1. Occupational Experiences & Participation
2. Perspectives on QoL
3. Strategies to Promote / Improve QoL



QSR NVivo8



The Prism of Occupational Justice



Individual Interviews

Table 1. Outline of Interview Guide questions.



**Final
Interview Guide**

Final Interview Guide	Topic	Example Questions
	Key questions on occupational experiences and perceptions of occupational participation	In what kind of activities do you participate? In what kind of activities do you wish/not wish to participate? How do you participate in activities (what kind of roles do you take)? How do you feel when you participate/not participate in activities?
	Key questions on perspectives and perceptions of QoL	What does QoL mean to you? How do you assess your QoL? Which factors affect your QoL? How is your QoL affected by participating/not participating in activities?
	Key questions on perceptions about ways to promote/improve QoL	How can your QoL be improved? How could you promote your QoL?



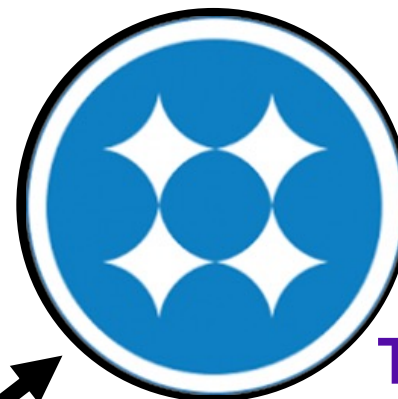
Research Methodology

Categories of Questions

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Verbatim transcripts proofread and imported into QSR NVivo8.



Systematic Content Analysis



N = 13 semi-structured interviews (M=9; F=4)

Average of **53 min.**

Audio recorded

Pseudonymized /

assigned unique interview identification codes

Demographic

Questionnaires

- ✓ OJ framework used to **identify** and **categorize occupational injustices.**
- ✓ **Reflective thinking** supported by collaboration with **supervising professor** as **critical friend.**
- ✓ Two coding rounds for **intracoder** reliability.
- ✓ **Iterative synthesis** of coded data led to final **thematic development.**



Model of Occupational Quality of Life





Defining Occupational Quality of Life (O-QoL)

Table 3. Conceptualization of the model of Occupational Quality of Life (O-QoL).

Model of Occupational Quality of Life (O-QoL) (Version 1)			Respondents (N = 13)
<u>Core Component: Occupation</u> Participating in Leisure Activities, Vocational Training, Employment, etc.,			I1, I2, I4, I5, I9, I10, I13
for personal/social	<u>First Domain:</u> Social Well-Being	Friends and social relationships	I2, I6, I7, I10, I12
		Family environment	I3, I4, I7, I8
		Social contribution	I9, I11, I12
development and	<u>Second Domain:</u> Emotional and Physical Well-Being	Emotional and physical health	I1, I5 I7, I8, I9, I11
		Sense of control, choice, autonomy, security, and privacy in life	I1, I6, I11
self- improvement	<u>Third Domain:</u> Material Adequacy	Financial status and political context	I5, I10, I12
		Living conditions and housing	I1

The individual's general feeling of well-being, which is determined by the involvement and active participation in desirable and essential for the individual occupations, i.e., everyday activities that promote the development of one's personality on a personal, social, emotional, physical and material level.



Occupation: Core Component of O-QoL

Table 4. Aspects of occupation influencing quality of life.

Occupational Aspects Enhancing Quality of Life (+)	Respondents (N = 13)
Social interaction and participation	I1, I2, I3, I4, I5, I6, I7, I8, I11, I12
Positive experiences/positive emotions	I1, I3, I5, I6 I7, I8, I9, I11, I12
Autonomy, privacy, security, sense of control over life, opportunities for free decision-making, and availability of choices	I1, I4, I6, I11, I12
Occupational Aspects Degrading Quality of Life (-)	Respondents (N = 13)
Patronizing, treating as inferior, continuous criticism, and disapproval	I1, I2, I3, I4, I7, I8, I11, I12
Deprivation/lack of participation and negative emotions	I1, I2, I4, I6, I7, I10
Monotony, repetition, passive routines, and inactivity	I1, I4, I10
Coercion and imposition	I1, I12

“R: What are the things that affect your life, whether good or bad?

S12: I’ve got my crew, and I chat with the staff here. We chill with my mates, hit up the yard to play some basketball or football ... I’m on the school football team, and I play defense. I don’t remember all the details though. I’ve gotten better at shooting now and have scored way more goals. It’s a blast! We play against other teams here and outside the school.

Sometimes we lose, sometimes we win, but we always have such a great time, and that makes me really happy!” (I12).



What a good life is and what isn't ?

R: What does a good life mean to you?

S9: *Difficult to answer.*

R: How is your life?

S9: *Good, good, very good.*

R: What makes a good life?

S9: **Going for walks and trips, going for a coffee at the neighborhood square, going to the sea in the summer.**

S11: I wish I could go out more often, like taking the car to visit friends and relatives, either at their homes or for coffee. I also enjoy going to the Mall. I want to become a barista and work at the Mall. I had a friend who worked there, and he told me it was great, but he has since moved to the island. (I11)

R: What do you think is very important for having a good time?

S3: **To be happy, to laugh,** to play with my brother or friends (laughs). To eat, go outside, watch movies. **I joke around with my brother, friends, and mom. I don't like being sad.** (I3)

S10: ...there's no one in my neighborhood to hang out with. I do have friends at school; they're nice kids, but we don't meet outside of school because we live far apart. I'd like to hang out with them outside of school, but it's difficult. It would be nice to go for walks, run, or exercise together. (I10)

S4: ...I'd rather be at school; I don't do anything at home. My friends are here, we hang out and talk a bit. (I4)



Assessing Occupational Quality of Life

Table 6. Assessment of quality of life.

Quality of Life Assessment Criteria	Respondents (N = 13)
Emotional state/health	I1, I2, I3, I5, I6, I9, I11, I12
Participation in entertaining social activities	I1, I2, I3, I5, I6, I9, I13
Financial status	I1, I2, I5, I12, I13
Social relationships (family, friends, community, etc.)	I2, I3, I10, I11, I12
Physical health	I2, I7, I13
Housing/living conditions	I1

“R: ...How is your life?

S1: Kind of crappy (laughs)?

Kinda unhappy and miserable?

*Okay, I don't sleep outside on the street, but **I would like the place***

where I sleep to be proper

home and not a hut! I want to

have my personal space, and

also heating because this isn't a house, it's the north pole!

R: How could you improve your life, make it better? What would you like to do?

S1: ...live on my own. I can live really easily alone, in the other flat where my cousins used to live.”

(I1)



Promoting Occupational Quality of Life

Table 7. Quality of life enhancement.

Means to Promote and Improve Quality of Life	Respondents (N = 13)
Academic advancement and growth/employment	I2, I3, I5, I6, I7, I8, I9, I11, I12
Social interaction and social activities	I1, I2, I3, I5, I7, I11, I12
Sexual expression and satisfaction	I2, I3, I6, I7, I11, I12
Continuous participation in various activities (e.g., physical exercise activities, sports, therapeutic/educational programs, and video games)	I1, I2, I3, I5, I6, I13
Disability elimination, resilience, and focus on personal needs	I1, I2, I3, I6, I4, I11
Social contribution/community serving	I2, I9
Family relationships/joint social activities	I4, I7
Housing, living conditions, and autonomy	I1, I7

“R: Is there something you’d like that would make your life better?”

S11: A lute or a violin so I could play songs for my girlfriend — I’d sing her love songs, like ‘my girl, I love you!’ I’ve learned piano and guitar, I can play loads of songs! Shall I grab the guitar from the music room and play you a bit? ... I’d like my girlfriend to come over so we could have sex, but if my mom caught us, she’d go mental and kill us both. But she does sex herself! She says we’re still too young and it’s not allowed. I don’t feel that young though — I tell her I’m old enough for sex, I even tell her I’m good at it, and she just goes, ‘Do whatever you want and leave me alone!’ (laughs).” (I11)



Occupations & Employment Improve O-QoL

Social Leisure Activities

Physical Exercise & Sports

Arts & Crafts

Video Gaming

Employment & Vocational Training

“S3: ...I really **enjoy making stuff and doing crafts.** We also play games like **tennis and bowling on the Wii; bowling is definitely my favorite.** We have a football team too! In every game I score three goals because **I'm really into football. I play as an attacker** and always look forward to game days so I can score a bunch of goals!” (13).

“R: How could you make your life better?

S7: ... **I'd love to be a carpenter, but whatever job they give me I don't have a problem.** I told the social service that I will leave, and they replied that if I am a good student they will let me leave. That's what they told me, they will find me work to gain my own money, not to get pocket money. To be able to get a coffee, a cheese pie, whatever I want!

R: How will this affect your life? If you find a job...

S7: **I want to find a proper job, not to be kicked out the next day, and I want to learn.** I believe I'll get a job; I believe so, I'm very good. **I won't sit at home all the time. I will get up every morning at seven o'clock and I will go to work,** and then I will attend school in the afternoon. Or a carpenter or a waiter I will become, and I will go to school at night and get up in the morning for work! **That's what I want, something to fill my day.**” (17)





Conclusions

While this study has significant limitations, notably in **sample diversity** and **external validation**, it lays a **promising foundation** for an **occupation-centred model of QoL** in the field of **IDs**:

- ❑ Through **participants' insights**, this research highlights the **integral role of meaningful occupations** in **promoting well-being**.
- ❑ The model of **Occupational Quality of Life (O-QoL) (version 1)** offers to **Occupational Therapy** an **empirically-based** and **occupation-centred alternative** for understanding and enhancing the **QoL** of **citizens with IDs**.



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 Occupational  Therapy



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Thank you for your attendance!

