

## Psychoeducational program to improve the quality of family life for adolescents and adults with intellectual disabilities and/or autism

*Programa psicoeducativo de qualidade de vida familiar de adolescentes e adultos com deficiência intelectual e/ou autismo*

*Programa psicoeducativo para mejorar la calidad de vida familiar de adolescentes y adultos con discapacidad intelectual y/o autismo*

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### Abstract

**Objective:** to evaluate the effects of a psychoeducational program on family quality of life for family members of adolescents and adults with intellectual disabilities and/or autism spectrum disorder. **Methods:** a quantitative, descriptive, quasi-experimental study was conducted with family members participating in a psychoeducational program in the first semester of 2023. Data collection was carried out using the *Family Quality of Life Scale for families with children with Intellectual and/or Developmental Disabilities* and descriptive reports, before and after the intervention. Data were analyzed using descriptive statistics of field diary entries made throughout the intervention. **Results:** six family members participated, most of whom had complete secondary school education (four mothers, one aunt, and one grandmother) who cared for individuals aged 10 to 21 years. Sixteen weekly one-and-a-half-hour meetings were offered. Slight variations were observed in family quality of life scores between pre and post-intervention periods, with maintenance or worsening in some domains. Conversely, field diary data indicated an increased perception of support, strengthened family bonds, and greater awareness of educational practices and care strategies. **Conclusion:** the program proved to be a viable strategy for promoting reflection and strengthening family relationships, indicating the relevance of family-centered interventions in the context of adolescence and adulthood for people with intellectual disabilities and/or autism.

**Keywords:** Adolescent; Intellectual disability; Autism Spectrum Disorder; Family; Quality of Life.

### Resumo:

**Objetivo:** avaliar os efeitos de um programa psicoeducativo de qualidade de vida familiar de familiares de adolescentes e adultos com deficiência intelectual e/ou transtorno do espectro autista. **Método:** estudo de abordagem quantitativa e descritiva, do tipo quase experimental, realizado com familiares participantes de um programa psicoeducativo, no primeiro semestre de 2023. A coleta de dados ocorreu por meio da *Escala de Qualidade de Vida Familiar para Famílias com Filhos com Deficiência Intelectual e/ou Desenvolvimento* e de relatos descritivos, antes e após a intervenção. Os dados foram analisados por estatística descritiva após leitura dos registros em diário de campo realizados ao longo da intervenção. **Resultados:** participaram seis familiares, na sua maioria com ensino médio completo (quatro mães, uma tia e uma avó) que cuidavam de pessoas de 10 a 21 anos. Ofertou-se 16 encontros semanais de uma hora e meia. Verificou-se variações discretas nos escores de qualidade de vida familiar entre os momentos pré e pós-intervenção, com manutenção ou piora em alguns domínios. Em contrapartida, os dados verificados pelo diário de campo mostraram ampliação da percepção de apoio, fortalecimento dos vínculos familiares e maior consciência sobre práticas educativas e estratégias de cuidado. **Conclusão:** o programa mostrou-se uma estratégia viável para favorecer a reflexão e o fortalecimento das relações familiares, indicando a relevância de intervenções centradas na família no contexto da adolescência e vida adulta de pessoas com deficiência intelectual e/ou autismo.

**Palavras-chave:** Adolescente; Deficiência intelectual; Transtorno do Espectro Autista; Família; Qualidade de vida.

### Resumen:

**Objetivo:** evaluar los efectos de un programa psicoeducativo de calidad de vida familiar dirigido a familiares de adolescentes y adultos con discapacidad intelectual y/o trastorno del espectro autista. **Método:** estudio de enfoque cuantitativo y descriptivo, de tipo cuasiexperimental, realizado con familiares participantes en un programa psicoeducativo, durante el primer semestre de 2023. La recogida de datos se llevó a cabo mediante la *Escala de Calidad de Vida Familiar para Familias con Hijos con Discapacidad Intelectual y/o del Desarrollo* y a través de relatos descriptivos, antes y después de la intervención. Los datos se analizaron mediante estadística descriptiva y tras la lectura de los registros del diario de campo elaborados a lo largo de la intervención. **Resultados:** participaron seis familiares, en su mayoría con educación secundaria completa (cuatro madres, una tía y una abuela), que cuidaban de personas de entre 10 y 21 años. Se ofrecieron 16 sesiones semanales de una hora y media de duración. Se observaron variaciones discretas en las puntuaciones de calidad de vida familiar entre los momentos pre y postintervención, con mantenimiento o empeoramiento en algunos dominios. En cambio, los datos recogidos en el diario de campo evidenciaron un aumento en la percepción de apoyo, fortalecimiento de los vínculos familiares y mayor conciencia sobre prácticas educativas y estrategias de cuidado. **Conclusión:** el programa se mostró como una estrategia viable para favorecer la reflexión y el fortalecimiento de las relaciones familiares, indicando la relevancia de las intervenciones centradas en la familia en el contexto de la adolescencia y la vida adulta de personas con discapacidad intelectual y/o autismo.

**Palabras-clave:** Adolescente; Discapacidad intelectual; Trastorno del Espectro Autista; Familia; Calidad de Vida.

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**INTRODUCTION**

**F**amily involvement has been associated with better outcomes in the social, emotional, and cognitive development of their children<sup>1</sup>, especially in the educational process, and is a positive predictor of the pedagogical and social performance of students with disabilities<sup>2</sup>. The use of specific practices based on research, with a family-centered focus, favors the adherence and engagement of families, with active participation in decision-making regarding more appropriate and personalized resources and support, favoring the autonomy and independence of children<sup>3</sup>.

Among the practices described by McWilliam<sup>4</sup> for effective work with families, there is the routine-based interview as an important support in identifying specific objectives for the family itself and its children, as well as family guidance groups for reflection on the interests and abilities of children to cope with the demands of daily family routines. Thus, the guidance offered to families is able to provide them with tools to understand the individual characteristics of their children, in addition to effective strategies to promote communication skills, social interaction, and autonomy<sup>1</sup>.

Psychoeducational guidance provided to families not only benefits the individual with autism spectrum disorder (ASD) or intellectual disability (ID), but also directly impacts the quality of relationships between parents and children<sup>5</sup>. By recognizing and responding more appropriately to the specific needs of their children, family members tend to reduce stress levels, overload, and create more welcoming and inclusive environments in different social contexts.

The behavior of parents is understood as a relevant variable in determining the behavior of their own children<sup>6</sup>. Considering that parents constitute significant contingencies for the behavioral repertoire of children and adolescents, these contingencies can be modified and, consequently, can produce positive changes in development and learning.

Family guidance has important implications for educational practice, since teachers who have the support and collaboration of families tend to better understand the individual needs of their students, favoring the adoption of more personalized and inclusive pedagogical strategies<sup>7</sup>. To ensure a collaborative educational approach<sup>8</sup>, coordination among school, family, and multidisciplinary team is essential, to develop individualized educational plans and offering systematic support that promotes equity in the classroom.

The quality of family interactions is associated with the use of positive educational practices, which contribute to the development of skills and autonomy in children<sup>8,9</sup>. In this context, practices that encourage reflection by family members on behaviors, developmental

stages, and values transmitted to children and adolescents are fundamental to building healthy family relationships.

Within the scope of family-centered practices, support refers to the use of natural resources present in daily family life, such as learning opportunities established in daily routines<sup>3,10</sup>. To evaluate the effects of these practices, it is necessary to use instruments capable of measuring the results obtained with families, with family quality of life being one of the main indicators used.

A Spanish study<sup>11</sup> presented a validated family quality of life scale for families with children with intellectual disabilities and/or developmental disorders, with a view to guiding interventions in the family-centered model. In the Brazilian context, the cultural adaptation of the Family Quality of Life Scale demonstrated adequate evidence of reliability and validity, recommending its use in research and professional practices<sup>12</sup>. However, a national integrative review<sup>13</sup> indicated that studies that directly address family quality of life are still scarce, with investigations focused on individual constructs of quality of life predominating.

Family quality of life has been considered a priority outcome in public policies and services aimed at people with intellectual disabilities and neurodevelopmental disorders, including autism spectrum disorder, especially after early childhood<sup>14</sup>. The persistent deficits in communication and social interaction, characteristic of these conditions<sup>15</sup>, can generate significant challenges in the educational process and in the organization of family dynamics.

Families of people with intellectual disabilities and/or autism frequently experience high levels of stress, which can be intensified by a lack of adequate information at the time of diagnosis, by the choice of interventions, and by the scarcity of specialized services<sup>16</sup>. These factors, combined with the continuous demands of care, can negatively impact family quality of life, affecting the family climate and emotional stability.

In this scenario, family guidance programs based on scientific evidence have proven to be promising strategies for promoting and strengthening more effective family practices that enhance the family's own resources, thus increasing its well-being<sup>17</sup>. However, it is observed that most publications on family-centered practices focus on early childhood and early intervention services<sup>3,4,16-23</sup> highlighting a gap in studies aimed at families of adolescents and adults with high support intensity.

Considering the relevance of family quality of life for the development of people with ASD and/or ID, the following become central: (a) understanding family dynamics; (b) identifying stressors that may compromise collaboration between family and school; and (c) implementing psychoeducational programs aligned with the specific demands of these families.

The characteristics associated with neurodevelopmental disorders may constitute additional stressors, requiring interventions that consider the family context broadly, and not reduced only to the person with ASD and/or ID<sup>11,12</sup>.

Expanding knowledge of family realities can provide opportunities to play a fundamental role in modifying the behavior of those under their care, thus extending learning to social and educational contexts. Given this scenario, this study aims to evaluate the effects of a psychoeducational program on family quality of life for family members of adolescents and adults with intellectual disabilities and/or autism spectrum disorder.

## METHODS

This is a quantitative and descriptive study, of the quasi-experimental type, with a pre and post-intervention design, without a control group, developed from the implementation of a family quality of life program, between February and July 2023.

Socioeconomic classification was performed according to the parameters established by the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística* - IBGE) in 2022<sup>24</sup>. The criteria that defined the participation/inclusion of family members in the study were: (a) that they were responsible for the care of a person diagnosed with ASD and/or ID; and (b) that they were willing to participate in 16 weekly meetings, lasting one hour and a half (01h30). The sampling was non-probabilistic, by convenience, composed of family members who voluntarily agreed to participate in the program and met the established inclusion criteria.

The meetings were held in person, in a room designated for group activities, located in a specialized clinic in the metropolitan region of ABC Paulista, in the state of São Paulo, Brazil, where individuals with ASD and/or ID received therapeutic follow-up with a multidisciplinary team. The program was developed over 16 consecutive weeks, with weekly meetings scheduled in advance. Data collection took place at two distinct times: (a) before the start of the intervention, at the first meeting, and (b) after the completion of the program, at the last meeting held with the participants.

The Family Quality of Life Scale was used to conduct the meetings. An adaptation of the *Escala de Calidad de Vida Familiar para Familias con Hijos con Discapacidad Intelectual y/o Desarrollo* (in English, Family Quality of Life Scale for Families with Children with Intellectual and/or Developmental Disabilities – PQIF)<sup>11</sup> was applied.

The use of the Family Quality of Life Scale<sup>11</sup> was evaluative and exploratory in nature, taking as a reference the validated original version and its adaptations. The translation used for

application with the participants aimed to facilitate the understanding of the items in the specific context of the program, not constituting a formal cross-cultural validation process.

As an assessment instrument, the Scale consists of 35 questions that address themes related to the emotions and situations experienced by the family member with the person diagnosed with ASD and/or ID under their care. Understanding aspects of daily interaction is necessary to understand the level of acceptance of the individual's condition with ASD and/or ID.

The 35 questions that make up the Scale are distributed across five evaluated factors: *Family Climate*; *Emotional Stability*; *Economic Well-being*; *Family Adaptation*; and *Family Resources*. Each factor receives a specific score, which is the sum of each of the items marked, using a Likert-scale response (in this case, from 1 to 5, where 1 = never; 2 = rarely; 3 = sometimes; 4 = often; and 5 = always). The Scale was applied at the first meeting, for initial measurement, and at the last meeting, for post-intervention evaluation<sup>11</sup>.

To monitor the intervention process, a field diary was used, structured and adapted from a Family Interaction Quality Program (PQIF)<sup>25,26</sup>. The field diary contained a guide with the thematic guidelines for each meeting, as well as space for descriptive recording of interactions, fragments of participants' speeches, reflections by the researchers, and suggestions arising from the discussions held.

An electronic questionnaire was used to record the meetings, completed after each meeting. The questions considered were: a) Full name, b) Date of the meeting, c) Meeting modality (in this case, all were in person), d) Structure and details of the interaction with the family, e) Functional analysis of behavior, as reported by the participant, f) Identification of the family's needs throughout the week, g) Descriptive record of the interaction with the family during the week, h) Feedback provided by the family during the week, i) Description of the resources sent by the family to the researcher (photos/videos/reports) during the week, j) Evaluation of the professional's level of satisfaction with her performance in family counseling.

The PQIF<sup>25,26</sup> was the guide for conducting the meetings, in which the following focuses were taken into account:

- a) Family relationships (considering the interactions between all family members, without exclusively emphasizing issues related to the person with intellectual disability and/or autism spectrum disorder);
- b) Practical and applicable approach, through concrete strategies and specific activities, implemented by families, based on the guidance provided in the group, aiming to improve the quality of family interactions;

c) Family well-being as a product of reflection on the definition of family relationships qualified as healthy. To this end, resources were provided to help participants improve communication between themselves and other family members; to resolve conflicts constructively; and to strengthen emotional bonds, aiming for a more positive and welcoming family environment;

d) Social relevance, based on the participants' understanding of the nature of family dynamics (changes and challenges such as stress, conflict, and disconnection) and the need to develop resources for coping and overcoming them.

The weekly meetings were scheduled according to a timetable released in advance, with days and times set according to the availability of the participants and in line with the availability of the researchers.

Each meeting was designed based on pre-defined directions and the topic addressed. The content of each meeting was recorded in the Field Diary. The routine established for each meeting followed the steps described in Chart 1.

**Chart 1.** Schedule of weekly meetings with family members of adolescents or adults with intellectual disabilities and/or autism spectrum disorder. ABC Paulista/SP, Brazil, 2023.

Meeting routine
Prior Preparation: Reflection on the theme of each meeting (sequence described in Table 2).
Introduction and Goal Setting by the Facilitator.
Group discussion: Sharing family perspectives and experiences related to the topic.
Practical Activities: Suggestions for exploring the topic in a tangible way.
Exploring Strategies and Tools for Dealing with Family Challenges.
Reflection and Feedback: Participants were encouraged to reflect on and provide feedback about the meeting.
Closing Remarks and Future Planning: Summary of the main points and consideration of expectations for the next meeting.

Chart 2 describes the thematic axes defined for the sequence of meetings, as proposed in the PQIF<sup>25, 26</sup>.

**Chart 2.** Thematic areas for meetings with family members of adolescents or adults with intellectual disabilities and/or autism spectrum disorder. ABC Paulista/SP, Brazil, 2023.

Sequence	Thematic Areas
1	Opening: Learning
2	Affectionate Relationships
3	Rules and Boundaries
4	Reinforcement
5	Punishment
6	Going Back in Time
7	Self-Knowledge and the Importance of the Model
8	Closure: Revision

The data obtained through the Family Quality of Life Scale were analyzed using descriptive statistics, considering measures of central tendency and dispersion, comparing the scores obtained before and after the intervention. The descriptive analysis of the research<sup>27</sup> used the records from the field diary and the electronic questionnaires. After reading the records, a discussion was held about the family quality of life of the investigated sample.

After acceptance, the program was explained and the Informed Consent Form (ICF) was read and signed. Participants were guaranteed the confidentiality of their identities; that is, that the information provided would only be used for scientific dissemination purposes, omitting data that would identify them.

## RESULTS

Chart 3 presents the sociodemographic characterization of the study participants and the individuals under their care. The sample consisted mostly of mothers, responsible for adolescents and adults diagnosed with autism spectrum disorder and/or intellectual disability, with different levels of education.

Six family members of adolescents and adults diagnosed with ASD and/or ID were included: four mothers, one aunt, and one grandmother. One of the mothers, identified as P1, was responsible for two children and, therefore, for subsequent analysis, the cases were designated as P1a and P1b, linked to a social project developed in a specialized educational institution, based on socioeconomic classification, in which the classes considered in this selection were: B2, C1, C2, and D.

**Chart 3.** Sociodemographic data of the participants and the individuals under their care. ABC Paulista, Brazil, 2023.

Participant	Age - Person under your care	Relationship to the person under your care	Educational level - Person under your care	Diagnosis - Person under your care
P1.a	10 years	Mother	5 <sup>th</sup> year (PE)	ASD
P1.b	12 years	Mother	7 <sup>th</sup> year (PE)	ASD
P2	14 years	Aunt	9 <sup>th</sup> year (PE)	ASD and ID
P3	16 years	Mother	2 <sup>nd</sup> year (SE - incomplete)	ASD
P4	21 years	Mother	SE - complete	ID
P5	23 years	Mother	SE - complete	ID
P6	21 years	Grandmother	SE - complete	ID

Key: PE = Primary Education; SE = Secondary Education; ASD = Autism Spectrum Disorder; ID = Intellectual Disability

In the Family Quality of Life Scale, the results are presented in Table 1. Individual scores are described in each of the five domains of the scale: *Family Climate*; *Emotional Stability*; *Economic Well-being*; *Family Adaptation*; and *Family Resources*, as well as the maximum possible values per domain.

**Table 1.** Scores of the Family Quality of Life domains in the assessment (AS) and reassessment (RAS) after the intervention. ABC Paulista, 2023.

Domain	Max.	P1 AS	P1 RAS	P2 AS	P2 RAS	P3 AS	P3 RAS	P4 AS	P4 RAS	P5 AS	P5 RAS	P6 AS	P6 RAS
Family Climate	60	46	43	56	57	56	56	60	60	54	53	57	53
Emotional Stability	40	28	25	35	36	35	35	39	40	34	33	36	33
Economic Well-being	40	28	27	35	36	35	35	38	40	33	33	36	33
Family Adaptation	55	45	42	51	52	51	51	55	55	50	50	52	50
Family Resources	45	35	34	42	43	42	42	45	45	41	40	43	40

**Key:** Max. = Maximum values; AS = Assessment (pre-intervention); RAS = Reassessment (post-intervention). Maximum possible values per domain: Family Climate (60), Emotional Stability (40), Economic Well-being (40), Family Adaptation (55) and Family Resources (45).

Table 2 presents the average scores in the initial and reassessment evaluations after the intervention. After analyzing the records, it was identified that, initially, the family members participating in the study responded to the first evaluation based on their prior knowledge of what they considered most appropriate from their perspective. After the intervention, when questioned about the decrease in points, they presented more critical responses regarding the evaluated dimensions, as they showed a certain lack of knowledge about them. The family resources dimension, for example, which involved statements about accessibility and satisfaction with services, showed a decrease in the score, and when questioned, they commented that they had a different perspective on the support needed for a person with ASD and/or ID.

**Table 2.** Average scores of family members in the assessment and reassessment on the Family Quality of Life Scale. ABC Paulista, Brazil, 2023.

Domain	Average AS	Average RAS
Family Climate	54.8	53.7
Emotional Stability	34.5	33.7
Economic Well-being	34.2	34.0
Family Adaptation	50.7	50.0
Family Resources	41.3	40.7

## DISCUSSION

The results obtained indicate that participation in the family quality of life program produced changes in the domains assessed by the Family Quality of Life Scale, although such changes did not occur homogeneously. The maintenance or reduction of scores in some cases can be understood in light of the process of criticality and knowledge of concepts of family

members in relation to their own conditions and life histories, social rights, and daily demands associated with the care of individuals with ASD and/or ID.

In this sense, family guidance and intervention programs tend not only to produce immediate behavioral changes, but also to favor reflective processes that impact how participants evaluate their reality, which can influence responses in standardized self-report instruments in the post-intervention period<sup>17,7</sup>. Thus, the stability or reduction of scores observed in some participants should not necessarily be interpreted as a lack of effect from the program, but as an expression of greater critical sensitivity to their own family experiences and those expected throughout the intervention process.

The accounts recorded throughout the meetings reinforce this interpretation, showing that the space for dialogue, access to systematized information, and the sharing of experiences among family members were central elements of the intervention process. Research indicates that group interventions based on family guidance favor the emotional strengthening of those responsible for care at home, even when quantitative indicators show discreet or non-linear variations<sup>7,12</sup>.

Regarding the domains evaluated, it was observed that aspects related to Family Climate and Emotional Stability showed greater variability between evaluation and re-evaluation, with higher scores in the re-evaluation. These domains are directly associated with the quality of daily interactions and how family members deal with situations of stress, emotional overload, and behavioral challenges, frequently reported in contexts of prolonged care<sup>18,12</sup>. Psychoeducational interventions can initially increase the perception of difficulties in these domains, as participants begin to identify dysfunctional patterns that were previously naturalized<sup>17</sup>.

The domains related to Economic Well-being and Family Resources showed less variation throughout the program, which is expected, considering that such factors depend, to a large extent, on structural and social conditions that go beyond the direct reach of short-term interventions<sup>10,21</sup>. Still, the meetings allowed for important reflections on access to rights, health services and institutional support, aspects widely discussed in the literature on families of individuals with disabilities<sup>12</sup>.

Family Adaptation, in turn, proved to be a domain sensitive to participation in the program, especially with regard to the reorganization of parenting practices and the greater involvement of participants in the educational and social activities of the individuals under their care. These findings corroborate studies that highlight the central role of family members

as active agents in modifying behaviors and promoting the development of people with ASD and/or ID<sup>10</sup>.

Family quality of life encompasses all the needs of the people who belong to the family group, sharing time together as a group, in addition to having the opportunity to achieve goals that are important to each person participating in the family system<sup>11</sup>.

Although family groups have their different approaches, the Scale<sup>11</sup> used brought together the central dimensions common to all of them. Emotional stability, which means feeling good, carrying out personal projects, having time for couple life (when there is conjugality in the family system), was the dimension that presented the highest score in the reassessment in three family members participating in the study (P1, P3 and P4), followed by the family climate, which involved questions about the quality of the relationship between all family members, how much they support and respect each other, with the highest score in the reassessment in P1 and P2.

In general, the results indicated that the Family Interaction Quality Program was a relevant strategy for strengthening family relationships, by favoring processes of reflection, exchange of experiences and expansion of the repertoire of parental strategies. These effects are consistent with evidence previously described in investigations about family interventions aimed at contexts of disability, reinforcing the importance of actions that consider not only the individual with a diagnosis, but the entire family system<sup>20,21</sup>.

## CONCLUSION

The findings of this study indicate that participation in the Family Interaction Quality Program was associated with subtle variations in family quality of life scores, measured before and after the intervention. Although the quantitative results did not show significant and homogeneous increases in all domains evaluated, participants' reports indicated meaningful changes in parenting practices, family communication, and family engagement in the educational and social routines of individuals with ASD and/or ID under their care.

These results should be interpreted considering the methodological limitations of the study, especially the small sample size, the absence of a control group, and the quasi-experimental design, factors that restrict the generalization of the findings. In addition, the use of self-report instruments may have been influenced by the increased critical awareness of the participants regarding their family conditions, which may explain the maintenance or reduction of scores in some cases at the post-intervention time.

Still, the qualitative data indicate that the program fostered important reflective processes, expanding the repertoire of parenting strategies and strengthening family bonds. These aspects reinforce the relevance of interventions that consider the family system as the central unit of care, especially in contexts of intellectual disability and autism spectrum disorder.

From a practical perspective, the results suggest that structured family guidance programs can contribute to strengthening family interactions and providing emotional support for caregivers, even when quantitative changes are subtle. Thus, the importance of implementing and expanding evidence-based programs, adapted to the specific needs of each family, is highlighted, as well as conducting future studies with larger samples, controlled designs, and longitudinal follow-up, in order to deepen the understanding of the effects of these interventions on family quality of life.

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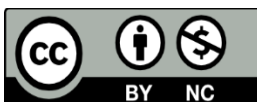
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