

## Challenges faced by community health workers in the self-care of adolescents with Down syndrome and Autism Spectrum Disorder

*Dificuldades dos agentes comunitários da saúde no autocuidado de jovens com Síndrome de Down e Transtorno do Espectro Autista*

*Dificultades de los agentes comunitarios de salud en el autocuidado de jóvenes con Síndrome de Down y Trastorno del Espectro Autista*

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### Abstract:

**Objective:** to analyze the knowledge and challenges experienced by community health workers in the self-care of adolescents with Autism Spectrum Disorder and Down syndrome. **Methods:** a descriptive cross-sectional quantitative study, using a structured questionnaire, conducted in 2024 in the municipality of Serrana, SP, Brazil, in the state of São Paulo, Brazil. **Results:** the main difficulties were: 50% lack of training, 50% insufficient communication, and 50% inability to interpret the adolescents' behavior. **Conclusion:** the findings show the need for continuing education, improved communication, as well as psychological support and a multidisciplinary approach.

**Keywords:** Community health workers; Self care; Trisomy 21; Autism spectrum disorder.

### Resumo:

**Objetivo:** analisar o conhecimento e desafios vivenciados por agentes comunitários de saúde no autocuidado de adolescentes na condição de Transtorno do Espectro Autista e Síndrome de Down. **Método:** Estudo quantitativo–descritivo, de caráter transversal, que utilizou questionário estruturado, realizado em 2024 no município de Serrana/SP. **Resultados:** das principais dificuldades: 50% falta de capacitação, 50% comunicação insuficiente e 50% não conseguir interpretar o comportamento do jovem. **Conclusão:** os achados mostram a necessidade de ação de educação permanente, melhoria na comunicação, bem como, suporte psicológico e atuação multiprofissional.

**Palavras-chave:** Agentes comunitários de saúde; Autocuidado; Trissomia do Cromossomo 21; Transtorno do espectro autista.

### Resumen:

**Objetivo:** analizar el conocimiento y los desafíos vivenciados por agentes comunitarios de salud en el autocuidado de adolescentes con Trastorno del Espectro Autista y Síndrome de Down. **Método:** estudio cuantitativo-descriptivo, de carácter transversal, que utilizó un cuestionario estructurado, realizado en 2024 en el municipio de Serrana, SP, Brasil. **Resultados:** entre las principales dificultades se identificaron: 50% falta de capacitación, 50% comunicación insuficiente y 50% incapacidad para interpretar el comportamiento del joven. **Conclusión:** los hallazgos muestran la necesidad de acciones de educación permanente, mejora en la comunicación, así como apoyo psicológico y actuación multiprofesional.

**Palabras clave:** Agentes Comunitarios de Salud; Autocuidado; Trisomía del Cromosoma 21; Transtorno del espectro autista.

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## INTRODUCTION

**P**uberty, which generally occurs between the ages of 9 and 14, is a period marked by intense physical, emotional, and social changes triggered by hormonal changes leading to the development of secondary sexual characteristics and the search for identity and belonging<sup>1</sup>. In this context, self-care plays a fundamental role in disease prevention, health promotion, and strengthening autonomy, involving practices such as personal hygiene, balanced nutrition, physical activity, and mental health care<sup>2,3</sup>.

For adolescents with intellectual disabilities, this process may be even more challenging due to limitations in cognitive functioning and adaptive behavior, which directly affect social skills and activities of daily living. In Brazil, it is estimated that approximately 5% of the population has some degree of intellectual disability<sup>4</sup>, with Down syndrome and Autism Spectrum Disorder (ASD) among the most prevalent conditions in this group. Down syndrome, resulting from trisomy of chromosome 21, is associated with delays in motor and cognitive development, affecting independence and self-care<sup>5</sup>. Autism Spectrum Disorder (ASD) is characterized by difficulties in communication, social interaction, and behavioral flexibility, which require greater support for performing daily tasks<sup>6,7</sup>.

In the context of Primary Health Care (PHC), the Family Health Strategy (FHS) plays a central role in promoting comprehensive care throughout the life course, focusing on the family, the territory, and educational actions<sup>8</sup>. Within this framework, Community Health Workers (CHWs) serve as a key link between the community and health services, conducting home visits, monitoring health conditions, and providing guidance on self-care practices<sup>9</sup>. In this context, CHWs are essential to strengthen the autonomy of adolescents with intellectual disabilities and support their families in educational and health promotion processes.

Despite this, CHWs face significant challenges when working with adolescents with Down syndrome or ASD, especially due to insufficient specific training, communication barriers, and the social stigma that still permeates this population<sup>10-14</sup>. The lack of adequate preparation hinders the adaptation of educational strategies to individual needs, limiting adolescents' understanding of guidance and reducing family engagement in care processes.

Continuous training, the adoption of accessible approaches, and community awareness become fundamental to expanding access to self-care and promoting autonomy<sup>11</sup>. Thus, this study aims to analyze the knowledge and challenges experienced by community health workers in the self-care of adolescents with Autism Spectrum Disorder and Down syndrome.

## METHODS

This is a cross-sectional, descriptive study with a quantitative approach. Community Health Workers (CHWs) linked to Family Health Strategy (FHS) teams in the city of Serrana/SP, Brazil, participated in the study in September 2024, after accepting the Informed Consent Form (ICF).

The inclusion criteria were: being a CHW working in the FHS, having direct contact with adolescents with Down syndrome and/or ASD, and being duly registered in the health units. CHWs who were absent from their activities during the data collection period were excluded.

The study was approved by the Ethics Committee of the Centro Universitário Estácio of Ribeirão Preto, CAAE 70621517000005581, following CNS Resolution No. 466/12. The ICF was made available at the beginning of the electronic questionnaire, ensuring prior reading and agreement before participation.

CHWs were invited to participate during their work activities. After receiving clarification about the study, each participant received a link to an electronic form created in Google Forms, containing the Informed Consent Form (as a prerequisite for participation) and questions regarding knowledge and difficulties encountered in supporting the self-care of adolescents with Down syndrome and ASD. The questionnaire included items on the professional profile of the CHWs, understanding of the specific needs of these adolescents, and barriers faced in the guidance process, allowing participants to respond voluntarily and anonymously.

Participation was voluntary, and only those who agreed to the terms and provided their free and informed consent could proceed to the questionnaire.

Data were tabulated using Microsoft Excel. Data entry validation procedures were performed using consistency checks, and duplicate entries were compared to ensure accuracy. Typing errors were identified and corrected. Data were analyzed and presented descriptively.

## RESULTS

Four primary healthcare teams were eligible, with the participation of 16 CHWs who had already had contact with adolescents with ASD and/or Down syndrome in their areas of operation. Of these, 11 reported difficulties. Table 1 shows that the main issues raised were: lack of training, difficulty communicating, and difficulty interpreting the behavior of adolescents with Down syndrome and ASD.

**Table 1.** Challenges faced by CHWs in managing adolescents with Down syndrome and ASD. Serrana/SP, 2024.

Difficulties	N*	Percentage (%)
Lack of training	8	50.0
Communication	8	50.0
Interpretation of behavior	8	50.0
Managing crisis situation	4	25.0
Resistance from families	4	25.0
Stigma and prejudice	1	6.3
No difficulties	5	31.3

\*The same respondent could answer more than one question.

Regarding preparedness for identifying signs of ASD, only 5 reported feeling prepared for identification, as shown in Table 2.

**Table 2.** CHWs' level of preparedness to identify ASD in adolescents. Serrana/SP, 2024.

Level of preparedness	N	Percentage (%)
Prepared	5	31.3
Partially prepared	5	31.3
Not prepared	6	37.5

Regarding preparedness for identifying signs of Down syndrome, 10 CHWs reported feeling prepared, while six considered themselves partially prepared, as shown in Table 3.

**Table 3.** CHWs' level of preparedness to identify signs of Down syndrome in adolescents. Serrana/SP, 2024.

Level of preparedness	N	Percentage (%)
Prepared	10	62.5
Partially prepared	6	37.5

Table 4 shows that 87.5% of CHWs do not have access to resources and support materials to assist in the care of adolescents with ASD and/or Down syndrome.

**Table 4.** CHWs regarding access to resources/support materials. Serrana/SP, 2024.

Access to resources	N	Percentage (%)
Has access	2	12.5
Does not have access	14	87.5

The Continuing Education in Health (CEH) actions listed were: in-person training, followed by lectures with specialists and a discussion session, as shown in Table 5.

**Table 5.** CHWs' preferences regarding continuing health education activities. Serrana/SP, 2024.

Type of training	N*	Percentage (%)
In-person training	12	75.0
Lectures with experts	9	56.3
Roundtable discussion	8	50.0
Online training	2	12.5

\*A single respondent could answer more than one question.

**DISCUSSION**

The results of this study showed that CHWs face significant challenges in relation to knowledge and approach to self-care of adolescents with Down syndrome and ASD, particularly due to a lack of specific training. Similar findings were identified in research carried out in PHC, which points to gaps in training for the management of neurodevelopmental conditions, reflecting structural weaknesses in continuing education<sup>10</sup>. Another study also showed that PHC professionals report insecurity and low preparedness for caring for people with ASD and intellectual disabilities, reinforcing that this is a global challenge<sup>11</sup>.

Difficulties in communication between CHWs and families identified in this study are also supported by national analysis, which points to communication barriers as one of the main obstacles to the longitudinal follow-up of individuals with intellectual disabilities and ASD in PHC<sup>14</sup>. Such barriers hinder the understanding of guidance and reduce families' adherence to self-care practices, which demonstrates the need for more accessible and culturally adapted strategies.

The lack of knowledge of CHWs about referral flows and about the support network and specialized services was also observed. Studies indicate that primary health care professionals are often unfamiliar with formal criteria and pathways for accessing rehabilitation and specialized care, resulting in significant delays in care<sup>2</sup>. International recommendations emphasize the importance of intersectoral communication and the strengthening of referral and counter-referral systems as essential strategies for improving care for individuals with ASD and intellectual disabilities<sup>6</sup>.

The absence of psychological support and the low support from multidisciplinary teams are highlighted. The emotional burden on CHWs is high, and caring for vulnerable families requires systematic support, including listening spaces and technical supervision<sup>3</sup>. Structured emotional support interventions reduce burnout and improve the quality of field professionals' performance<sup>4</sup>.

These findings have important implications for primary health care management. Continuing health education actions are needed, with content that includes: accessible communication, early identification of signs of ASD and Down syndrome, behavior management, and health education strategies. Studies indicate that practical, in-person, and simulation-based training has a greater impact on changes in professional practice<sup>7</sup>.

The availability of standardized protocols, quick-reference guides, and accessible educational materials for CHWs can promote uniformity in guidelines and strengthen

educational actions. Successful experience shows that creating appropriate workflows improves professional safety and reduces waiting times for specialized services<sup>8</sup>.

The integration of PHC with sectors such as education, social assistance, and mental health, as proposed in national and international guidelines, is also fundamental to ensuring comprehensive care aligned with the needs of these adolescents. Intersectoral collaborative networks reduce inequalities in access and increase the autonomy of families<sup>4</sup>.

In addition, strengthening communication with families should be a priority. Family-centered interventions, such as conversation circles, qualified home visits, and structured guidance, increase understanding of self-care practices and promote positive bonds<sup>5</sup>.

In summary, the results show that the work of CHWs with adolescents with ASD and Down syndrome requires structured investments in training, emotional support, development of educational materials, clear protocols, and greater intersectoral coordination. These actions can contribute to safer, more humane, and more effective practices, reinforcing the strategic role of Community Health Workers and improving the comprehensive care offered to the population.

## CONCLUSION

Among the difficulties listed by the Community Health Workers (CHWs) related to the self-care of adolescents with Down syndrome and Autism Spectrum Disorder, the most prominent were insufficient specific training, communication barriers, and challenges in the socio-family context.

The professionals have limitations in identifying and managing the needs of these adolescents, which compromises the effectiveness of self-care guidelines. The lack of adequate technical preparation directly interferes with the quality of care offered within the scope of Primary Health Care (PHC).

Communication barriers also proved relevant in terms of the interaction between CHWs, adolescents, and their families. The presence of stigmas and low family understanding of the adolescents' conditions negatively impact adherence to the proposed guidelines. These factors reinforce the complexity of care and the need for more integrated approaches.

Among the methodological limitations of the study, the cross-sectional design, which does not allow establishing causal relationships, as well as the use of a structured questionnaire, which may restrict the depth of the responses, stood out. Furthermore, the fact that the research was conducted in a single municipality limits the generalization of the results to other realities.

In turn, the results of this study have important implications for practice and for the thematic area, highlighting the need for investments in continuing education, technical support,

and strengthening multidisciplinary work. Such actions are fundamental to improving the care provided and promoting more effective, inclusive, and humanized assistance to young people with Down syndrome and Autism Spectrum Disorder.

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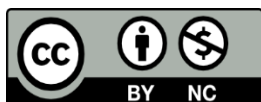
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