

ORIGINAL ARTICLE

The Association between POTADS community support and activities of daily living independence among adolescents with Down syndrome in urban Indonesia: A cross-sectional study

Alinda Aura Zahra* | Iis Aisyah | Rafika Rosyda

^a Department of Nursing, Indonesia University of Education, Sumedang Campus, Sumedang, West Java, Indonesia

* Corresponding Author: alindaaurazahea@upi.edu

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ABSTRACT

Introduction: Functional independence is a key developmental milestone for adolescents with Down syndrome (DS), yet evidence from low- and middle income countries examining community based influences on daily living abilities remains scarce. POTADS, a parent-led organization in Indonesia, provides emotional, informational, and instrumental support, but its direct impact on adolescents' functional independence has not been empirically evaluated.

Objectives: To analyze the association between POTADS community support and independence in activities of daily living (ADL) among adolescents with DS in an urban Indonesian setting.

Methods: A cross-sectional study was conducted among 53 adolescents aged 10–18 years who were active members of POTADS. Community support was measured using a modified social support scale, and ADL independence was assessed using the adapted self-care domain of the Pediatric Evaluation of Disability Inventory. Data were analyzed using Spearman's rho due to non-normal distribution.

Results: Nearly all parents reported high levels of community support (98%), whereas most adolescents reported high levels of ADL independence (89%). A statistical analysis revealed no significant association between community support and ADL independence ($r_s = -0.156$; $p = 0.264$). Minimal variability in responses and ceiling effects may explain the lack of correlation.

Conclusions: POTADS community support was not directly associated with ADL independence in this study. Nonetheless, the community may provide indirect benefits, such as empowerment for parents. Including skill-focused, family-based training in nursing and community initiatives could potentially improve adolescents' functional independence.

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1. Introduction

Down syndrome is primarily caused by trisomy 21, an extra copy of chromosome 21, which results in overexpression of genes located on this chromosome (Aluzeib et al., 2024). DS is one of the most common genetic causes of intellectual disability and continues to present challenges in the development of functional skills, particularly independence in activities of daily living (ADL) (Achmad et al., 2023; Custodio et al., 2023; Faradz, 2021). During adolescence, the ability to perform ADL becomes increasingly important as individuals with DS move toward greater autonomy and social participation (Aranti & Pristiano, 2024). Delays in ADL independence have been linked to limitations in motor coordination, cognitive processing, and self-regulation (Chmiel et al., 2024). Reported that children with DS score lower in domains related to self-care, mobility, and social functioning (Anugrah et al., 2025). Davis and Oliver (2023) further emphasized that early communication and emotion regulation skills strongly influence later adaptive behaviors, including ADL performance.

Environmental support also plays an important role in shaping children's functional outcomes (Wahyudi et al., 2020). Van der Heide et al. (2023) found that adolescents with DS who are actively involved in household routines tend to develop stronger functional and social skills. Alongside this, parental well-being contributes significantly to the consistency of daily training

and stimulation provided at home. Hasanah et al. demonstrated that social support enhances parents' emotional well-being and strengthens their ability to adapt to the challenges of raising a child with DS. (Rizqi et al., 2023) noted that emotional warmth, acceptance, and informational support help parents develop more positive coping strategies. Similarly, showed that support from fellow parents improves family interactions and enriches children's opportunities for social engagement. Despite these findings, most studies focus on parental well-being or family stress, while research linking community support to functional independence, specifically ADL in adolescents with DS remains limited (Czaja et al., 2021).

In Indonesia, the *Persatuan Orang Tua Anak dengan Down Syndrome* (POTADS) community represents a unique parent led support system that provides educational sessions, emotional encouragement, peer learning, and various family centered activities. This community model reflects a culturally grounded mechanism where parents collaborate to exchange knowledge and strengthen caregiving practices. Although POTADS is widely recognized and active across urban settings, there is currently no empirical evidence assessing whether perceived community support relates to the level of ADL independence among adolescents with DS (Yulhan, 2021). National studies have largely focused on early childhood, stress management, or parental coping, but not on adolescents aged 10-18 years or their functional independence.

This issue reflects not only a local research gap but also a broader global gap. Evidence examining how community support influences functional outcomes in adolescents with DS is scarce, particularly in low- and middle-income countries where families often rely on community-based structures due to limited access to formal rehabilitation services (Jubaedah, 2024). Investigating how a parent led organization such as POTADS contributes to functional independence is therefore relevant for Indonesia and extends the global dialogue on family empowerment and community-based disability support.

Based on this background, the present study aims to analyze the association between POTADS community support and ADL independence among adolescents with down syndrome in an urban Indonesian context. The study offers theoretical value by contributing to the limited body of literature examining community support as a potential factor influencing functional independence. It also provides practical contributions for nursing and community programs by highlighting the potential role of parent led organizations in supporting family centered care for adolescents with DS.

2. Methods

This study employed a cross-sectional design to examine the association between community support and activities of daily living independence among adolescents with down syndrome in urban Indonesia. The research was conducted within the POTADS community in Jakarta, a parent led organization that regularly provides developmental, educational, and peer support activities for families. A total of 53 parents of adolescents with down syndrome participated in this study, each representing one family unit. The accessible population consisted of 53 eligible adolescents aged 11–18 years who actively attended activities at the Rumah Ceria Down Syndrome (RCDS) center. Therefore, all were included using a total population sampling approach. The minimum recommended sample size for correlational studies ($n \geq 50$) was met, and the inclusion of all eligible participants provided adequate statistical power to detect meaningful associations between the study variables.

Two instruments were used to measure the research variables. Community support was assessed using an adapted 10 item social support scale measuring emotional, informational, and instrumental support provided by the POTADS community. ADL independence was measured using a 15 item adapted self care and functional independence component of the Pediatric Evaluation of Disability Inventory (PEDI) modified, which evaluates adolescents independence in daily self care tasks. Both instruments underwent a structured cultural adaptation and psychometric evaluation process, including forward translation, expert review by pediatric nursing academics experienced in developmental disabilities, and pilot testing with parents of adolescents with Down syndrome from another POTADS branch. This process ensured linguistic

clarity, contextual appropriateness, and suitability of the instruments for use in the study population.

Construct validity was assessed using corrected item total correlations with a minimum acceptability threshold of $r \geq 0.30$. For the community support scale, nine of the ten items demonstrated acceptable item total correlations; one item showed insufficient variance due to highly homogeneous responses and was excluded from the final analysis. All fifteen items of the ADL independence scale met the validity threshold and were retained. Internal consistency reliability testing demonstrated excellent reliability for both instruments, with Cronbach's alpha values of 0.927 for the community support scale and 0.939 for the ADL independence scale.

Data collection was conducted in person at the RCDS center, where each parent completed the questionnaires independently with the researcher present to provide clarification when needed. All completed questionnaires were checked immediately to ensure completeness. Community support scores were categorized into high, moderate, and low levels based on percentile distributions, while ADL independence scores were categorized into high and moderate levels following established functional performance guidelines.

All statistical analyses were conducted using JASP version 0.18. The distribution of the two main variables was assessed using the kolmogorov smirnov normality test, which indicated that both variables were non-normally distributed ($p < 0.001$ for each variable). Given the ordinal measurement level and non-normal data distribution, the Spearman rho correlation test was selected as the appropriate non parametric method to examine the association between community support and ADL independence. No missing data were identified, therefore, no imputation was required. Potential confounders such as age and sex were examined descriptively but were not controlled analytically due to sample size limitations; this limitation is acknowledged for future research.

3. Results and Discussion

Table 1 presents the demographic characteristics of children with Down Syndrome in POTADS programs. Most were male (53%, $n = 28$), while females accounted for 47% ($n = 25$). The largest age group was 18 years (49%), followed by 16 (15%) and 14 (13%). Only one child (2%) was 10 years old. The sample primarily comprised older adolescents, aligning with the study's focus on functional independence in the 10–18 age range.

Table 1. Characteristics of Children with Down Syndrome

Characteristics	Category	n	%
Gender	Male	28	53
	Female	25	47
Age	10	1	2
	11	3	6
	13	3	6
	14	7	13
	15	3	6
	16	8	15
	17	2	4
	18	26	49
Total		53	100

Table 2 details parents' perceptions of POTADS community support. Nearly all respondents (98%) reported high support, with one (2%) rating it as moderate. None rated support as low. This indicates a consistently supportive POTADS community.

Regarding ADL independence, Table 2 shows that most children (89%, $n = 47$) had high independence, while 6 (11%) were in the moderate category. None were low in independence. These distributions suggest a modal profile pairing high community support and high ADL independence.

Table 2. Distribution of POTADS Community Support and ADL Independence

Variables	Category	n	%
Community Support	High	52	98
	Moderate	1	2
	Low	0	0
Total		53	100
ADL Independence	High	47	89
	Moderate	6	11
	Low	0	0
Total		53	100

Table 3 presents the numerical descriptive statistics for community support and ADL independence among adolescents with Down syndrome. The community support variable showed a mean of 40 with a standard deviation of 3, indicating relatively low variability across respondents. The median score of 40 and the IQR of 38-42 further demonstrate that most parents consistently perceived high levels of support from the POTADS community. The minimum and maximum scores (32-45) confirm a ceiling effect, with many participants scoring near the upper range of the scale.

For ADL independence, the mean score was 26 (SD = 4), with a median of 27 and an IQR of 24-30, suggesting that most adolescents demonstrated moderate to high independence. Although variability in ADL scores was slightly higher than that of community support, the maximum score (30) and clustering around the upper quartile also indicate a partial ceiling effect. The restricted score ranges in both variables support the interpretation that overall sample responses were highly concentrated near the higher end of the measurement scales.

Table 3. Descriptive Statistics of Community Support and ADL Independence

Variable	Mean	SD	Variance	Median	IQR (Q1-Q3)	Min	Max
Community Support	40	3	10	40	38-42	32	45
ADL Independence	26	4	17	27	24-30	14	30

Table 4 shows that the correlation between community support and ADL independence was weak and not statistically significant ($r_s = -0.156$; $p = 0.264$). Although the coefficient indicates a slight negative direction, the magnitude is very small and does not reflect a meaningful association. The non-significant result is likely influenced by the limited variability and ceiling effects observed in both variables, where most respondents reported uniformly high community support and moderate to high ADL independence. This restricted range reduces the sensitivity of the correlation test and may obscure potential relationships. Therefore, the lack of significance should be interpreted as a limitation of the data distribution rather than evidence of an actual absence of association.

Table 4. Correlation Between POTADS Community Support and ADL Independence

Variables	r_s	p	Interpretation
Community Support to ADL Independence	-0.156	0.264	Not Significant

This study examined the relationship between community support from POTADS and independence in ADL among adolescents with Down syndrome. The results showed that parents viewed community support as consistently high, while adolescents demonstrated moderate to high independence in ADL. However, correlation analysis revealed a weak and insignificant relationship between the two variables ($r_s = -0.156$; $p = 0.264$). Item-level analysis showed that emotional support received the highest approval from parents, while instrumental support, the subtype most closely related to functional skill development showed greater variation.

This study found that parents perceived community support in POTADS as consistently high, which aligns with findings showing that social support improves parental confidence and

empowerment. Community based programs have similarly been shown to strengthen caregiving readiness and psychological well-being among parents of children with DS. More recent studies also highlight that structured parent activities enhance coping and caregiving competence. Regarding ADL independence, the generally high functional ability observed in this study is consistent with evidence that mobility, physical activity, and home-based routines support daily living skills in children with DS (Masaki et al., 2024). Parental self-efficacy and structured parenting have also been associated with improved self-care abilities (Rahayu et al., 2023).

However, the absence of a significant relationship between community support and ADL in this study contrasts with reports showing that caregiving style and executive functioning more directly influence ADL performance. Other research suggests that community support primarily enhances parental empowerment rather than directly improving children's functional skills (Spann et al., 2023). Overall, this study aligns with literature showing strong community benefits for parents but differs from studies where social support has a measurable impact on children's ADL outcomes.

The absence of a significant relationship can be attributed to both measurement and contextual factors. First, both variables showed ceiling effects, with scores clustered at the upper range, limiting variability and reducing the sensitivity of the correlation test. Second, there was an imbalance across subdimensions of community support, that emotional support was uniformly high, whereas instrumental support, such as practical assistance and ADL related guidance, was more varied (Baney et al., 2022). Because instrumental support is the component most directly linked to functional skill development, its inconsistent distribution may have weakened the overall association with ADL independence. Third, ADL development relies heavily on home-based routines, parental scaffolding, and repeated practice, which occur primarily within the family rather than through community programs (Amer, 2024; Van Deusen et al., 2024). These factors together help explain why high community support did not translate into higher measurable ADL independence.

From the perspective of Social Support Theory (House, 1981), support consists of emotional, informational, and instrumental components. The dominance of emotional support in this study reflects strong affective bonds within POTADS but highlights a gap in instrumental support, which is theoretically the component most directly linked to skill acquisition. Using the lens of family centered care, community support should empower parents to provide structured, developmentally appropriate experiences that promote functional independence. The uneven distribution of instrumental support may limit parents' capacity to translate emotional encouragement into behavioral strategies that enhance ADL performance. These theoretical perspectives help explain why high perceived support does not necessarily produce corresponding gains in ADL independence.

Based on the findings, a potential pathway can be proposed in which community support—particularly instrumental support—enhances parental empowerment and caregiving competence, enabling parents to provide more structured and consistent ADL practice at home, which in turn supports greater functional independence in adolescents. However, because instrumental support in this study was not uniformly high, this pathway may not have operated optimally within the POTADS context, contributing to the non-significant statistical association observed.

The divergence between this study and those reporting significant associations may be explained by differences in cultural context, family dynamics, and the structure of community programs (Abdollahi & Rasoulpoor, 2024). In Indonesia, parents often rely more on family-based routines than community led interventions, which may reduce the direct influence of community support on children's ADL outcomes. Additionally, POTADS places strong emphasis on emotional and informational support, while instrumental support, which is more closely tied to functional skill acquisition, may vary across families. Other studies also suggest that factors such as parenting style, executive functioning, and the intensity of home-based practice play a more immediate role in shaping ADL performance. These contextual and developmental differences likely contribute to the lack of a measurable association in this study despite high overall support.

This study has several limitations that should be considered when interpreting the findings. The ceiling effect in both community support and ADL scores reduced score variability and limited the sensitivity of the correlation analysis. The use of self-report questionnaires may have introduced social desirability bias, particularly in items related to community involvement. The study was also conducted within a single community setting (POTADS Jakarta) and used a cross-sectional design, restricting generalization and preventing causal conclusions. Additionally, important factors such as parenting style, therapy intensity, and level of disability were not measured, which may influence ADL independence.

The findings of this study highlight the theoretical importance of distinguishing between emotional and instrumental components of social support, as emotional support alone may not directly influence functional outcomes in adolescents with down syndrome. From a practical perspective, the results suggest that health professionals and community organizers should prioritize strengthening instrumental support, such as structured ADL training, hands on coaching, and consistent skill-based routines that parents can apply at home (Tjin et al., 2022). Enhancing these practical supports may help translate high levels of parental empowerment into more effective daily living skill development for children, while also guiding POTADS and similar communities to design programs that more directly target functional independence (Tamiemie & Sa'adah (2025).

4. Conclusion

The findings of this study indicate that, although community support within POTADS is consistently perceived as strong, such support does not exhibit a direct association with adolescents' ADL independence (Caldwell & Dorris, 2024). This suggests that emotional and informational support may enhance parental resilience but do not necessarily translate into functional gains without the presence of structured, skill oriented instrumental assistance (Cao et al., 2021; Pakpahan et al., 2021). These results underscore the broader implication that community based programs, both in Indonesia and internationally, should prioritize practical, evidence based interventions that facilitate the transfer of parental empowerment into consistent ADL practice at home (Taylor, 2020). Future research should adopt longitudinal or intervention focused designs and examine potential mediating mechanisms, including parental self efficacy, therapy intensity, and executive functioning, to better elucidate pathways through which support systems influence functional independence in individuals with DS (Sarafino & Smith, 2020).

Ethics approval and consent to participate

This study was reviewed and declared ethically feasible by the Health Research Ethics Commission with approval number No. 04/KEPK/FITKes-Unjani/X/2025. Prior to data collection, the researcher provided a clear explanation of the study's purpose, procedures, potential benefits, and possible risks. All respondents confirmed their willingness to participate by signing an informed consent form, indicating that they understood their rights as participants and voluntarily agreed to take part in the research.

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