

**THE PATH TO INDEPENDENCE:  
CHALLENGES AND THE IMPORTANCE  
OF SUPPORTED HOUSING FOR YOUNG PEOPLE  
WITH DEVELOPMENTAL DISABILITIES**

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**Abstract**

The aim of this study is to examine the needs and challenges faced by children and young people with developmental disabilities, as well as their families, in the process of achieving independence in a context where community-based support is insufficiently developed. Particular attention is given to assessing the potential significance of supported housing as a mechanism that could enable a more independent and better quality life. The study was conducted in Niš in two stages. The quantitative component involved 45 parents who filled out a structured questionnaire regarding life skills, independence, and future aspirations. The qualitative component comprised four focus groups involving 20 individuals ages 13 through 30, two of which also included 12 parents to support participants with limited verbal expression. The data were examined utilising descriptive statistics, normalisation techniques, and thematic analysis. Findings indicate that adolescents exhibited the highest degree of autonomy in personal hygiene and the utilisation of mobile devices and the internet, whereas the least independence was observed in financial management, domestic upkeep, and meal preparation. Parents underscored the necessity for systemic assistance, including supported housing, personal aides, employment centres, and community services. A significant majority (86.7%) concurred that supported housing would meet the needs of young individuals with disabilities in Niš. These results highlight that the path to autonomy is complex and contingent on both individual capacities and the availability of community-based support. Establishing supported housing and associated community services is crucial for promoting social inclusion and autonomous living.

**Key words:** disabilities, deinstitutionalisation, supported housing, independent living, social inclusion.

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## ПУТ КА САМОСТАЛНОСТИ: ИЗАЗОВИ И ЗНАЧАЈ СТАНОВАЊА УЗ ПОДРШКУ ЗА МЛАДЕ СА РАЗВОЈНИМ ТЕШКОЋАМА

### Апстракт

Циљ овог истраживања је да испита потребе и изазове са којима се суочавају деца и млади са развојним тешкоћама у процесу постизања самосталности, као и њихове породице, у условима недовољно развијене подршке у заједници. Посебан акценат стављен је на процену потенцијалног значаја услуге становања уз подршку као механизма који би омогућио независнији и квалитетнији живот. Истраживање је спроведено у Нишу у две фазе. Квантитативни део обухватио је 45 родитеља који су попунили упитник о животним вештинама деце и младих, степену њихове самосталности и будућим аспирацијама. Квалитативни део састојао се од четири фокус групе са 20 младих учесника узраста од 13 до 30 година, од којих су у две групе укључени и родитељи (укупно 12) ради подршке учесницима са ограниченом вербалном експресијом. Подаци су обрађени коришћењем дескриптивне статистике, техника нормализације и тематске анализе. Резултати показују да су адолесценти показали највећи ниво аутономије у личној хигијени и коришћењу мобилних уређаја и интернета, док је најмања самосталност забележена у управљању новцем, вођењу домаћинства и припреми оброка. Родитељи су истакли потребу за системском подршком, укључујући становање уз подршку, персоналне асистенте, центре за запошљавање и услуге у заједници. Значајна већина родитеља (86,7%) сагласна је да би становање уз подршку задовољило потребе младих са тешкоћама у Нишу. Ови налази указују да је пут ка аутономији сложен и зависи како од индивидуалних капацитета, тако и од доступности подршке у заједници. Успостављање становања уз подршку и пратећих услуга у заједници кључно је за унапређење социјалне укључености и самосталног живота.

**Кључне речи:** тешкоће у развоју, деинституционализација, становање уз подршку, самосталан живот, социјална укљученост.

### INTRODUCTION

The reform of the social protection system in the Republic of Serbia has been intensively implemented since 2011, with one of its key goals being the transition from a model that relies on residential institutions to one centred on community-based services. This process is known as deinstitutionalisation (Grigaitė, et al., 2024; Rosenthal, et al., 2021; Mulheir, 2012). Deinstitutionalisation derives its normative foundation primarily from the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006). This Convention, the first legally binding international treaty of its kind, emphasises the right to live in the community as a fundamental right. The three key elements of the Convention are: the right to choose; individualised support that promotes inclusion and prevents isolation; and the adaptation of services intended for the general population to ensure accessibility for people with disabilities.

The effects of the aforementioned reform can be discussed in many ways, but in this paper it is observed in the context of young people with disabilities. From this perspective, it can be said that the reform was accompanied by numerous difficulties due to insufficient and territorially unevenly developed support services, as well as services for the independent life of these young people and their equal participation in the community (Petrušić, 2017). One of these services is the service of supported housing. The purpose of supported housing services for people with physical disabilities or intellectual or mental disabilities is to help and support them in gaining the greatest possible degree of independence that enables a higher quality of independent life in the community (Regulation on Detailed Conditions and Standards for the Provision of Social Protection Services, 2013; Art. 89). Supported housing provides appropriate accommodation, professional assistance, and support for the user's complete independence and inclusion in the community. Supported housing is provided to prevent the use of residential care services.

In 2022, the Republic of Serbia adopted the Strategy for Deinstitutionalisation and the Development of Social Protection Services in the Community for the Period 2022–2026. This strategic document is intended to guide the reform process and, above all, contribute to various target groups, including persons with disabilities, in realising their right to live in the community. However, more than two years after its adoption, there are few indicators of its effectiveness. Data from the Institute for Social Protection (2023) show that the number of institutionalised users is not decreasing, while community-based services that would support their stay in or return to the community remain largely unavailable. More specifically, the supported housing service is currently established in only four local self-government units - Kula, Šabac, Bogatić, and Pančevo - serving just 27 users. Social care services such as this one are decentralised, allowing local self-government units to develop services tailored to the needs of their communities. In the context of the City of Niš, where this study was undertaken, the supported housing services for young and adults with disabilities has not been acknowledged or incorporated into the City of Niš Social Protection Strategy for the Period 2022–2026.

### *THEORETICAL BACKGROUND*

The theoretical background of this paper consists of the framework of children's and human rights, as well as the social model of disability. These perspectives enable a deeper understanding of the needs and challenges faced by young people with disabilities in the process of becoming independent, as well as the role of families, institutions, and the community in providing adequate support.

The approach to children's and human rights starts with the fact that children and young people with disabilities are equal holders of rights guaranteed by international and domestic legal acts. The key documents that provide the basis for the analysis are the United Nations Convention on the Rights of the Child (CRC) (United Nations, 1989) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Article 23 of the CRC recognises the right of children with disabilities to special treatment and support that enables them to participate fully in the community, while Article 27 emphasises the child's right to an adequate standard of living adequate for the child's physical, mental, spiritual, moral, and social development, which also includes support for independence. The CRPD, especially Article 19, emphasises the right of persons with disabilities to live in the community and the obligation of states to provide appropriate support services to enable them to live independently and socially. This framework makes it possible to consider supported housing not only as a social care service but also as a fulfilment of fundamental human rights.

Unlike the medical model that views disability as an individual deficit, the social model of disability points out that obstacles to the independence of young people with disabilities do not arise only from their functional limitations but from social, economic, and political barriers that make their inclusion difficult (Oliver, 1990; Barton, 2009; Barnes & Mercer, 2010; Grbović & Vučinić, 2018).

### *CHALLENGES OF INDEPENDENT LIVING FOR YOUNG PEOPLE WITH DISABILITIES*

The process of growing up brings with it numerous physical and emotional changes. In addition, there are changes in roles, relationships, and expectations (both in the family, among peers, at school, at work, and in the wider community). When we talk about the growing up of children people with disabilities, this process is characterised by additional challenges. Namely, previous research on this topic informs us about the complexity of these challenges, as well as about the possible reasons for them. Namely, these young people, in addition to numerous personal challenges such as physical, sensory, cognitive, and communicative limitations, face serious barriers in their communities (Shulz et al., 2022; Trainor et al., 2019; Lindsay et al., 2015; Wehmeyer & Palmer, 2003). Some of these barriers are social stigma and discrimination, lack of support in the process of education, then employment, as well as general participation in community life.

Research shows that the quality of the transition to an independent life of young people with disabilities is primarily conditioned by the availability of personalised services, life skills training, and family and commu-

nity support. As this target group does not represent a homogeneous group, the so-called individualised approach or personalisation of services is needed in order to respond to their specific needs. Also, previous research highlights the importance of the role of family and community in providing support to these young people and preserving, but also developing, their capacities for community integration and independent living (McConkey et al., 2023; Wang & Singer, 2016). Young people with disabilities who are on the way to independence often do not have developed social skills, nor access to adequate services that would enable them to gradually acquire essential life skills (Townshley et al., 2010).

### *METHODS*

This research focuses on the needs of children and young people with disabilities and their families during the transition to independence, as well as the availability of social protection and community support. Its aim is to identify challenges faced in this process, explore the perceptions of young people and their parents, assess the need the supported housing service, and provide recommendations to enhance support and quality of life for this population.

Research questions:

1. What are the needs of children and young people with disabilities in the process of becoming independent?
2. What challenges do families face in caring for children and young people with disabilities, especially in the period of independence?
3. What skills for independent living do children and young people with disabilities have, and which should be improved?
4. How do parents, families, and young people see the future and the possibility of living independently?
5. What is the role of the local community and institutions in supporting children and young people with disabilities in their independence?

The research was conducted in two phases during December 2024 and January 2025 in the City of Niš. The first phase involved a quantitative survey with 45 parents of children and young people with disabilities, collecting data on the children's characteristics, independence in life skills, support for independence, and future plans. An original questionnaire was developed for the study, informed by prior research and established criteria for evaluating living skills in young individuals with developmental disabilities (e.g., Townshley et al., 2010; Wehmeyer & Palmer, 2003). It encompassed the subsequent domains associated with independent living: maintaining personal hygiene, maintaining the living space, nutrition, money management, use of community resources, use of mobile phones and the internet.

The questionnaire included closed-ended questions with rating scales to assess perceived levels of support. For each activity, parents were asked to assess their child's ability by choosing one of three response options: 'independent,' 'with support,' or 'does not perform.' This format allowed for capturing both the level of autonomy and the need for assistance. Data were collected via Google Forms and analysed in Microsoft Excel using descriptive statistics (frequencies and percentages). Responses to open-ended questions were analysed using thematic analysis (Brown & Clarke, 2006).

The majority of children and young people are boys (80%), aged 10 to 27, with the largest group being those aged 12 to 15 (58%). The most common disabilities are Autism Spectrum Disorder (68.9%), multiple disabilities (8.9%), Down's syndrome, and intellectual disabilities (6.7% each). Additionally, 17.8% of children have associated health conditions, including cerebral palsy, asthma, dermatitis, epilepsy, and heart disease. Among school-aged children and young people, 69.4% attend regular schools, while 30.6% attend special schools.

Participants were not categorised by the degree of intellectual disability, nor were results analysed according to these categories. The focus was on current functional independence and daily living skills, providing a snapshot of autonomy relevant for assessing potential readiness for supported housing services. This approach, applied in both the quantitative and qualitative phases of the study, aligns with the study's aim to identify needs and challenges in the transition to independent living, regardless of diagnostic categories, and to inform recommendations for enhancing support and quality of life.

The second, qualitative phase involved four focus groups with 20 young people (14 boys and 6 girls, aged 13–30), designed to complement the survey findings from parents. Groups were formed to ensure diversity in gender, age, and type of developmental disability, providing a range of perspectives. Focus groups allowed young participants to express their views on issues directly affecting their lives and offered deeper insight into areas previously reported by parents. Group dynamics helped stimulate discussion and encourage engagement. A focus group protocol was developed specifically for this research guided conversations on independence and future aspirations, particularly regarding housing and employment. For participants with limited verbal abilities, parents joined two groups (12 parents), and visual aids (e.g., illustrations of household tasks and transportation) facilitated communication.

In the data analysis, young people's statements about their independence in certain skills were rated on a scale of 1 to 3 (1 being the highest and 3 being the lowest level of support). For each skill, the ratings were summed and normalised so that they could be compared. For the purposes of this research, the *Min-Max* normalisation method (OECD, 2008) was used. This method normalises the indicators to an identical range of values [0, 1], as shown in equation 11.1, where  $X_i$  represents the individual indi-

cator value,  $X_{min}$  the minimum indicator value in the observed set of values for that indicator,  $X_{max}$  the maximum indicator value in the observed set of values for that indicator, and  $X_{i,0-1}$  the normalised indicator value of the indicator.

$$X_{i,0-1} = \frac{X_i - X_{min}}{X_{max} - X_{min}}$$

Additionally, part of the data collected in this part of the research was processed through thematic analysis by two researchers who independently analysed the obtained material (Brown & Clarke, 2006).

All participants gave oral consent after being fully informed about the study objectives, data collection, and result presentation. Anonymity, confidentiality, and privacy were ensured through name encryption and removal of identifying information (Craswell, 2014).

## RESULTS

### *Quantitative Part of the Research*

Parents were asked about the level of independence of their children in various areas. In general, children and young people are most independent in activities such as dressing (64%), using mobile phones (71%), and using computers (64%). Conversely, the majority require adult support for tasks including maintaining personal hygiene (58%), taking medication (58%), keeping the living space clean (60%), and using public transport (51%). Certain activities are most often not performed independently by the participants, such as managing money (56%) and using household appliances, including washing machines (60%) and irons (80%). For some tasks, an equal proportion of children and young people either require adult assistance or are unable to perform them independently, for example, shopping and meal preparation (45% in each case). These findings highlight the variability in independence across daily activities and underscore the areas where targeted support is most needed.

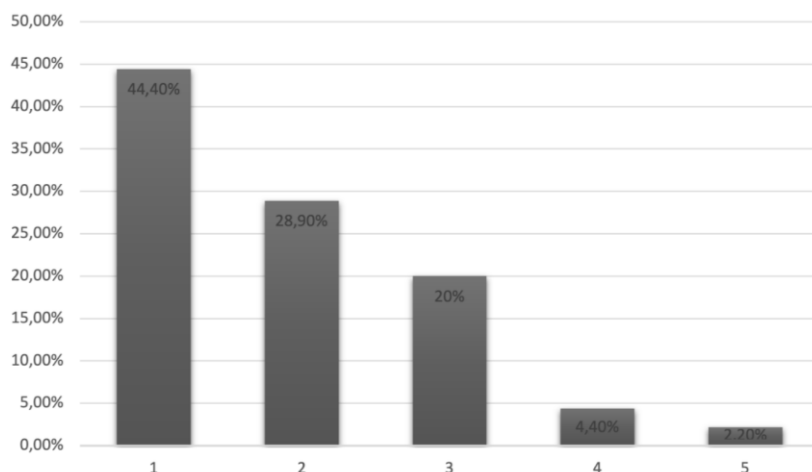
Parents' responses regarding factors that could enhance their children's independence can be grouped into three main categories:

- Support: available professional support for both parents and child, parents who have more time and knowledge to guide them, greater community support
- More frequent exposure to these activities both at home and in the community
- Resources: personal assistants for all children and for young people, centres or day-cares where their knowledge and skills will be improved.

The survey asked parents about plans for their child's future independent living or about plans when parent could no longer care for them.

Most (73.3%) had considered it but lacked a concrete plan, while 15.6% had a specific plan and 11.1% had not thought about it.

When assessing their child's current readiness for independence, the majority gave the lowest rating on a 1–5 scale (Chart 1).



*Chart 1. Parents' Perception of Their Child's Readiness for Independent Living*

Potential solutions that parents suggest could help young people with disabilities live independently include:

- Development and improvement of social care services (supported housing, personal assistance, foster care for adults, day care)
- Development of job centres
- Development of life skills programs
- Support and change at the community level (increased community awareness, work on community integration).

When asked about familiarity with supported housing service, 43.2% of parents reported having sufficient information, 36.4% had heard of it but lacked details, and 20.5% were unfamiliar. After a description of the service, 86.7% believed it would meet the needs of young people with disabilities in Niš, with the remainder unsure and none negative. Regarding their own child, 66.7% responded positively, 31.1% were unsure, and 2.2% responded negatively.

#### *Qualitative Part of the Research*

In this section, the results related to the level of independence of children and young people in different areas, as well as the future aspirations of the children and young people themselves and their parents, will be presented.

The average personal hygiene score was 0.77, showing relatively high development in this skill, though individual differences were notable (0.00–1.00) (Table 1). Three participants scored 0.50 or lower due to developmental or health challenges: one with moderate intellectual disability and comorbidities (cerebral palsy, epilepsy), and two with Down syndrome or autism, described by parents as insufficiently skilled. Independence was highest in toilet use, while bathing required the most support. Some parents felt their children could be more independent but emphasised correct execution (e.g., washing hair).

Table 1. Personal hygiene

	Toilet	Washing face and brushing teeth	Bathing	SUM	Norm.
Y1	3	3	2	8	0.83
Y2	3	2	2	7	0.67
Y3	3	3	2	8	0.83
Y4	3	2	2	7	0.67
Y5	3	3	3	9	1.00
Y6	3	3	3	9	1.00
Y7	3	3	3	9	1.00
Y8	3	3	3	9	1.00
Y9	3	2	2	7	0.67
Y10	3	3	3	9	1.00
Y11	3	3	3	9	1.00
Y12	3	3	3	9	1.00
Y13	2	2	2	6	0.50
Y14	2	3	2	7	0.67
Y15	3	3	2	8	0.83
Y16	2	3	2	7	0.67
Y17	2	2	2	6	0.50
Y18	1	1	1	3	0.00
Y19	3	3	2	8	0.83
Y20	2	3	2	7	0.67
Sum	53	53	46		0.77

Legend: Scores per item are coded on a 1–3 scale (1 = highest dependence, 3 = highest independence). SUM (row) = total score per respondent across all items; SUM (column) = cumulative score for each item across all respondents; Norm. = normalised score (0–1); Y = respondent code.<sup>1</sup>

The average score for maintaining the living space was 0.33, indicating low mastery (Table 2). Only one respondent reached the maximum, while another scored 0.90, showing that few have highly developed skills. Weakest areas were using a washing machine and ironing, with dishwashing rated slightly higher. The most independent participants had mild intellectual disability or Asperger’s syndrome.

<sup>1</sup> Legend applies to Tables 1–6.

Parents point out that other children in the family often do not do housework either, so they do not associate this exclusively with difficulties in development. Also, some of them, out of concern for safety, limit children's use of chemicals and iron. They also state that since the birth of their children, they have faced numerous challenges, while they lacked support and education on how to encourage them to become independent.

There are so many fears and unknowns from their birth, so many stresses in the health and education system, that when we overcome that, we don't think about these ordinary, everyday things that they could certainly learn.

(P10)

Although parents try to maintain a routine, they notice that children make the most progress when they leave it, such as going on excursions and camps, where they function in a group and with the support of teachers or personal assistants. As one parent says, "Every risk is worth the effort" (P5).

Table 2. Maintaining the living space

	Washing dishes	Vacuuming	Cleaning	Washing machine	Ironing	SUM	Norm.
Y1	2	1	1	1	1	6	0.10
Y2	1	1	1	1	1	5	0.00
Y3	3	2	2	1	1	9	0.40
Y4	3	1	2	1	1	8	0.30
Y5	3	3	3	3	3	15	1.00
Y6	1	1	1	1	1	5	0.00
Y7	1	2	2	1	1	7	0.20
Y8	3	3	3	2	1	12	0.70
Y9	1	3	1	1	1	7	0.20
Y10	3	3	2	1	1	10	0.50
Y11	3	3	2	1	3	12	0.70
Y12	3	3	3	2	3	14	0.90
Y13	1	1	2	1	1	6	0.10
Y14	2	1	2	1	1	7	0.20
Y15	3	3	2	2	1	11	0.60
Y16	1	1	1	1	1	5	0.00
Y17	2	2	1	1	1	7	0.20
Y18	1	1	1	1	1	5	0.00
Y19	3	1	1	1	1	7	0.20
Y20	1	1	1	1	1	5	0.00
Sum	41	37	34	25	26		0.33

The average nutrition score was 0.41, indicating moderate food preparation skills (Table 3). Only three respondents scored higher, and one reached the maximum, while eight scored 0.00 or 0.13, showing need for support. Sub-category scores were mostly uniform. Preparing tea and coffee is notable, as

some participants practice these skills in an inclusive café, independently or with support, using a coffee machine. Such skills, aided by volunteers, promote work engagement, social interaction, and income generation.

Similar to home maintenance, many young people have limited opportunities to practice independently because parents perform these tasks, often due to safety concerns with stoves and knives. While microwave use is common, stoves, ovens, and hot plates are used less frequently.

Table 3. Nutrition

	Procurement of groceries	Independent preparation of meals	Cutting ingredients	Preparing coffee and tea	SUM	Norm.
Y1	2	1	1	1	5	0.13
Y2	2	1	1	1	5	0.13
Y3	2	2	2	3	9	0.63
Y4	2	1	1	1	5	0.13
Y5	3	3	3	3	12	1.00
Y6	2	1	1	3	7	0.38
Y7	2	2	2	3	9	0.63
Y8	3	3	3	2	11	0.88
Y9	2	1	2	3	8	0.50
Y10	2	2	2	2	8	0.50
Y11	2	2	2	2	8	0.50
Y12	3	2	2	3	10	0.75
Y13	1	1	1	1	4	0.00
Y14	2	1	1	2	6	0.25
Y15	2	3	2	3	10	0.75
Y16	1	2	1	1	5	0.13
Y17	1	1	1	1	4	0.00
Y18	1	1	1	1	4	0.00
Y19	2	2	1	3	8	0.50
Y20	1	1	1	2	5	0.13
Sum	38	33	31	41		0.41

The average score for mobile phone and internet use was 0.59, indicating moderate to high competence (Table 4). Four respondents use phones and navigate the internet independently, while three scored 0.00. Participants were most independent in making calls and sending messages, though half do not engage in these activities. Social media use is limited, often restricted by family members due to perceived risks.

I was 12 years old at the time, and a man who was 44 years old wrote to me. Since then, my brother has been controlling my social networks.

(Y10)

One participant with autism spectrum condition prefers online socialising, as it avoids the discomfort of face-to-face interactions.

Table 4. Use of mobile phones and the internet

	Calls and messages	Social networks	Internet	SUM	Norm.
Y1	3	1	2	6	0.50
Y2	1	1	1	3	0.00
Y3	3	1	2	6	0.50
Y4	3	2	1	6	0.50
Y5	3	3	3	9	1.00
Y6	3	3	3	9	1.00
Y7	3	3	2	8	0.83
Y8	3	3	3	9	1.00
Y9	3	1	2	6	0.50
Y10	3	3	2	8	0.83
Y11	3	3	2	8	0.83
Y12	3	3	3	9	1.00
Y13	3	1	2	6	0.50
Y14	2	1	2	5	0.33
Y15	3	1	3	7	0.67
Y16	1	1	1	3	0.00
Y17	1	1	1	3	0.00
Y18	2	1	2	5	0.33
Y19	3	3	2	8	0.83
Y20	2	1	3	6	0.50
Sum	51	37	42		0.59

The average score for money management was 0.30, indicating generally low competence (Table 5). The maximum observed was 0.83, but no participant achieved full independence. Eleven respondents scored below the norm, reflecting limited skills in recognising prices, paying, saving, and heavy reliance on others. Only five could pay the bills with support, and none independently. Four participants manage pocket money independently, while others either lack pocket money or need assistance.

The average score for community resource use was 0.49, showing modest development (Table 6). No participant reached the maximum, but two scored 0.80, demonstrating effective understanding and use. Most scored 0.40–0.50, indicating basic skills with need for support. Subcategory scores were largely uniform. Crucially, no one is completely barred from community activities, largely due to family efforts, mainly by mothers, to involve their children despite limited systemic support. Many mothers are unemployed, affecting family finances and children's opportunities for participation.

Limited independent resource management increases reliance on family. Some parents devised safe ways for their children to visit stores or use public transport, but societal ignorance and fear remain major barriers. One parent observed: "Our kids are typically feared by the community. They give them odd stares, as though they are a miracle of some sort" (P10).

Table 5. Money Disposition

	Paying bills	Going shopping	Pocket money	SUM	Norm.
Y1	1	1	2	4	0.17
Y2	1	1	1	3	0.00
Y3	1	1	2	4	0.17
Y4	1	1	2	4	0.17
Y5	2	2	3	7	0.67
Y6	1	2	2	5	0.33
Y7	1	2	2	5	0.33
Y8	2	3	3	8	0.83
Y9	2	2	2	6	0.50
Y10	1	2	2	5	0.33
Y11	1	2	2	5	0.33
Y12	2	3	3	8	0.83
Y13	1	1	1	3	0.00
Y14	1	1	1	3	0.00
Y15	2	3	3	8	0.83
Y16	1	1	1	3	0.00
Y17	1	1	1	3	0.00
Y18	1	1	1	3	0.00
Y19	1	2	1	4	0.17
Y20	1	2	1	4	0.17
Sum	25	34	36		0.30

Table 6. Using community resources

	Public transport	Post office	Health centre	Cultural institutions	Sports institutions	SUM	Norm.
Y1	2	2	2	2	2	10	0.5
Y2	2	1	2	2	2	9	0.4
Y3	2	2	2	2	2	10	0.5
Y4	2	2	2	2	2	10	0.5
Y5	3	2	2	3	3	13	0.8
Y6	2	2	2	2	2	10	0.5
Y7	2	2	2	2	2	10	0.5
Y8	3	2	2	3	3	13	0.8
Y9	2	2	2	2	2	10	0.5
Y10	2	2	2	2	2	10	0.5
Y11	2	2	2	2	2	10	0.5
Y12	3	2	2	3	3	13	0.8
Y13	2	2	2	2	2	10	0.5
Y14	2	1	2	2	2	9	0.4
Y15	3	2	2	1	1	9	0.4
Y16	2	1	2	2	1	8	0.3
Y17	2	2	2	1	1	8	0.3
Y18	2	1	2	2	1	8	0.3
Y19	2	2	2	2	1	9	0.4
Y20	2	1	2	2	2	9	0.4
Sum	44	35	40	41	38		0.49

Parents also admitted they often overlook opportunities to develop skills, trying to complete tasks quickly due to children's impatience or fear of mistakes. As one mother explained:

I'm often in a crowd, and we go in to quickly finish what needs to be done. He doesn't like to wait in lines, so I either avoid going with him or I try to finish as soon as possible.

(P9)

According to one mother, technological advancements have made things easier, such as paying bills and using public transportation, but parents' anxiety that their children would make a mistake limits their chances of learning these skills.

Table 7 compares skills for independent living across all domains. Highest average scores were in personal hygiene (0.77) and mobile phone/internet use (0.59), while lowest were in money management (0.30) and living space maintenance (0.33). This summary confirms previous results, highlighting key areas where additional support is needed.

*Table 7. Comparative analysis of the development of skills important for independent living*

Skills – observed areas	Average value
Personal hygiene	0.77
Use of mobile phones and the internet	0.59
Using community resources	0.49
Nutrition	0.41
Maintaining the living space	0.33
Money Disposition	0.30

**About the future.** Young people who understood the concept of independent living, particularly supported housing, reported it would suit most of them. This idea was especially appealing to those who have known each other for a long time and work together in an inclusive café, which helps them build social connections, gain economic empowerment, and develop life skills.

“That’s a really good idea. If we all lived together, it would be really intriguing” (Y5, Y6, Y7).

Many participants expressed the desire to start their own families and live independently.

“I can see myself residing with my spouse and kids. In my dream, it's in a house in a peaceful area of the city” (Y8).

“I’ll have an apartment in the centre of the city if my office is there. If living with a roommate doesn’t work out, then it's just the cat and me” (Y12).

Parents and youth emphasised the importance of employment for independence, noting challenges such as employers' lack of awareness, un-

suitable workplaces, and gaps in skills after graduation. Secondary schools in Niš offer vocational programs for students with developmental disabilities, yet parents report that even in protected workshops, practical skill acquisition is limited:

She is learning hairdressing, but in actuality she sits and observes what others are doing. It's more like purchasing time to be among her peers and socialise, rather than learning something and expecting to be able to do it eventually.

(P6)

Only two participants attend an electrical engineering school, which provides a potential pathway to future employment. However, parents note that formal schooling alone is not enough for acquiring all necessary practical skills, and they plan to supplement education in the future with mentoring through private lessons to ensure their children are fully prepared for the labour market.

Parents highlighted that employers often only recognise physical disabilities and lack understanding of the adaptations needed for young people with autism. The Law on Professional Rehabilitation and Employment of Persons with Disabilities (2009) establishes employers' obligations for the employment of persons with disabilities (Article 24.), yet parents note that many employers are unaware or interpret disability narrowly:

What is the most common, if not always the only, pictogram representing disability? A wheelchair, possibly a hearing aid, implying that we frequently limit disability to those manifestations and fail to comprehend the complexities of the term.

(P3)

Regarding the future, many parents feel anxious and uncertain, trying to focus on daily life instead: "Believe me when I say I must not think about the future... If we think, we swiftly fade away, and we cannot fade away because of them. That's why we take each day as it comes" (P10).

Parents see siblings as potential future resources but stress it should not be their obligation: "Even if he ends up in an institution, I am relieved that he has a brother and sister who will visit him" (P4).

After explaining supported housing, all parents agreed on its importance, though some expressed concerns about its suitability: "I absolutely think it's for him. I just wouldn't like that place of residence to turn into a ghetto" (P9).

## DISCUSSION

The findings reveal uneven levels of independence among children and young people with developmental disabilities. Quantitative data show that participants are most independent in personal hygiene (64%), using mobile phones (71%), and computers (64%), while they require the most

support in money management (56%), use of household appliances (60–80%), and maintaining living space (60%). These trends are consistent with normalised qualitative results, where hygiene (0.77) and digital skills (0.59) emerged as the strongest domains, and money management (0.30) and household chores (0.33) as the weakest.

The high level of personal hygiene can be explained by the fact that these skills are integrated into everyday family routines and continuously reinforced from early childhood. In contrast, managing money or household tasks requires real-life practice and exposure, which are often limited due to parental overprotection, safety concerns, and a lack of opportunities for autonomous engagement. Many parents noted that their children rarely handle money independently or perform household chores, as these activities are perceived as risky or too demanding. This suggests that limited practice, rather than lack of ability, restricts development in these domains.

Nutrition (0.41) and use of community services (0.49) fall in the middle range, showing that independence in these areas depends largely on family involvement and accessibility of community resources. Parents emphasised that systematic exposure to everyday tasks and access to personal assistants or day programs could significantly strengthen these competencies.

Age differences also play a crucial role in the acquisition of independence skills. Although statistical testing was not conducted, qualitative insights indicate that older participants (18–30 years) show higher levels of autonomy, especially in hygiene, digital literacy, and social interaction, compared to younger participants (13–17 years), who are still developing in areas such as money management and nutrition. This finding aligns with developmental expectations and previous research showing that independence grows with age and accumulated experience (Wehmeyer & Palmer, 2003; Schulz et al., 2022). The absence of formal measurement of these differences represents a methodological limitation that future research should address.

Overall, the integration of quantitative and qualitative data highlights the variability of independence and identifies domains requiring structured support. Skills reinforced through daily routines or technology use develop more easily, while those linked to practical and social functioning lag behind due to environmental and systemic barriers. Early, consistent, and structured interventions—especially community-based programs—are essential for developing core independence skills and preparing youth for supported living.

When it comes to the future, parents express persistent anxiety and uncertainty. Key barriers include the lack of accessible workplaces, limited employer awareness, and insufficient systemic support. Services crucial for independence—such as personal assistance, day programs, or supported housing—remain unavailable. Many participants, particularly those no longer in education, are effectively invisible to institutions, leaving families as the sole providers of support.

Supported housing, although recognised by 86.7% of parents as necessary, is still not available in Niš. Parents see it as a service that could bridge the gap between dependence and autonomy, enhancing skill development and social inclusion. Young people themselves, when familiar with the concept, largely share this view, recognising its potential to enable independent and dignified living. These findings reinforce the need for systemic development of supported housing and related community services as vital components of inclusive social policy.

### *CONCLUSION*

The research indicates that young people with developmental disabilities in Niš show uneven independence across daily activities. They are most independent in personal hygiene and using mobile phones or computers, but rely heavily on support for money management, household chores, and nutrition. Skills reinforced in daily routines or by peers develop more readily, while competencies requiring structured practice and community engagement remain underdeveloped.

Parents expressed concern about their children's future, emphasising the lack of adapted workplaces, low employer awareness, and scarce systemic support. Supported housing, recognised by 86.7% of parents as essential, is currently unavailable, representing a key barrier to autonomy. Young people familiar with the concept agreed that it would enhance social inclusion, skill development, and independent living.

The findings highlight systemic gaps in services such as supported housing, personal assistance, and day programs, which restrict independence and social participation. From a human rights perspective, these gaps impede the right to community-based living, as defined by the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. Obstacles to independence arise from societal and systemic deficiencies rather than the abilities of young people themselves. Without community-based support, families remain the sole source of care, limiting opportunities for autonomy and social justice.

### *LIMITATION OF RESEARCH AND FUTURE RESEARCH*

The methodological design of this study limits the generalisability of its findings. The sample was small, localised, and heterogeneous in age, communication, and functioning, and participants were not grouped by level of intellectual disability, which restricts a deeper understanding of differences in support needs. Since none of the participants used supported housing, the study cannot assess or compare its effects on autonomy. Future research should include comparative studies with users of supported housing, examine settings where such services already exist, apply stand-

ardised measures of functional independence, and rely on larger and more diverse samples. Drawing on international evidence and human rights frameworks may further support the development of community-based services, including supported housing. Despite these limitations, the study offers important insights that may inform local policy regarding the needs of this population and guide future interventions.

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## **ПУТ КА САМОСТАЛНОСТИ: ИЗАЗОВИ И ЗНАЧАЈ СТАНОВАЊА УЗ ПОДРШКУ ЗА МЛАДЕ СА РАЗВОЈНИМ ТЕШКОЋАМА**

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### **Резиме**

Циљ овог истраживања је да испита потребе и изазове са којима се суочавају деца и млади са развојним тешкоћама у процесу постизања самосталности, као и њихове породице, у условима недовољно развијене подршке у заједници. Посебан акценат стављен је на процену потенцијалног значаја услуге становања уз подршку као механизма који би омогућио независнији и квалитетнији живот, с обзиром на то да ова услуга у Нишу тренутно није успостављена.

Квантитативни део обухватио је 45 родитеља, а подаци су прикупљени упитником о самосталности у животним вештинама, подршци и будућим плановима. Квалитативни део обухватио је четири фокус групе са 20 младих, уз укључивање родитеља у две групе, коришћењем протокола који покрива независност и будуће тежње, нарочито у становању и запошљавању.

Резултати показују висок и умерен ниво самосталности у личној хигијени и коришћењу мобилних телефона и интернета, док су најмање независни у управљању новцем, кућним пословима, припреми оброка и коришћењу ресурса заједнице. Вештине које се учвршћују у свакодневним рутинама или уз вршњачку подршку лакше се стичу, док компетенције које захтевају структурирану праксу и ангажовање у заједници остају недовољно развијене. Старосне разлике су очигледне: старији учесници боље користе дигиталне вештине, личну хигијену и учествују у заједници, док су млађи више зависни у финансијским и сложенијим активностима. Родитељи истичу потребу за системском подршком, приступом ресурсима и излагањем младих активностима кроз личне асистенте и дневне програме.

Недостатак становања уз подршку и других услуга које промовишу независност указује на системски пропуст у обезбеђивању инклузије. Млади који су разумели концепт изразили су да би ова услуга била погодна за већину њих, посебно због развоја животних вештина, економске оснажености и друштвене интеграције. Ограничења студије укључују величину узорка, географску специфичност и непостојање података о степену интелектуалне инвалидности. Упркос томе, рад пружа значајне увиде у потребе младих са тешкоћама у развоју и даје смернице за развој политика и програма који подржавају самосталан живот, са фокусом на становање уз подршку.