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## **Original Article**

# "The experiences and needs of persons with disabilities in using paratransit services"

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#### ABSTRACT

*Background:* Persons with disabilities do not yet experience equality with the rest of the population when using transportation. Paratransit services take over transportation for persons with disabilities when public transportation cannot be used or can only be used to a limited extent. The usefulness of these services remains limited due to financial and structural reasons.

*Objective*: This study aims to identify the experiences of persons with disabilities with paratransit in Switzerland, explores their needs and verifies facilitators and barriers to the use of paratransit services. Furthermore, perceived experiences of how barriers and facilitators of transportation influence the participation in different areas of life of these persons are examined.

Methods: In this study, we adopted a qualitative approach with four online focus group discussions and one physically present discussion group, including 31 participants overall. We collected data between July and October 2021 and analyzed the data using content analysis according to Mayring (2015).

Results: Overall, persons with disabilities experience paratransit as important and appreciated this alternative to public transportation. Specifically, the services' need is individual for each person and depends on different facilitating factors (e.g., habits, health condition, activities, safety, accessibility, service) and barriers (e.g., costs, weather conditions).

*Conclusions*: The need for paratransit services is highly individual and impacts participation in different life areas. On one hand, the federalist system in Switzerland supports a local and cultural embedment, but on the other hand leads to difficulties concerning transportation beyond the close local environment and for longer distances.

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Transportation is an essential function for various areas of life, such as participating in professional and social life and being mobile in an independent way.<sup>2</sup> Paratransit services are an important transportation option for persons with disabilities (also older, chronically ill, or frail persons) who cannot use public transportation or can only use it to a limited extent. They contribute to transportation equality for persons with disabilities.

According to the UN Convention on the Rights of Persons with Disabilities (UN CRPD), measures should be taken to eliminate disadvantages in the use of transportation: "State parties shall take

effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost".<sup>3</sup>

In Switzerland, paratransit services are regionally organized, and providers are non-profit associations or private driving services. Different cost units such as health insurance, disability insurance and supplementary benefits cover the costs for certain travel purposes. Costs for other travel purposes are financed by the cantons (political regions) or by donations and are often subject to tight quotas and/or costs are paid out-of-pocket. Costs for transportation are defined by the providers themselves and are in general above the price for public transportation but lower than those

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of a taxi service. There is a variability in the offer of paratransit services among the 26 Swiss cantons and the paratransit services themselves. They differ in organization and coordination, availability, financing, and costs and could lead to social exclusion or involuntary transportation disadvantages. 4 This raises the question of how persons with disabilities experience the use of paratransit services? Whereas experiences of persons with disabilities with using public transportation are already studied, the experiences with paratransit services are rarely investigated. <sup>2,5–13</sup> The existing literature covers financial aspects or focus on one special user group. 14-17 To close this knowledge gap and to ensure equality in the use of transportation for persons with and without disabilities, the aim of this study is to gather more knowledge on how persons with disabilities experience paratransit services. Knowledge is needed about their needs and about facilitators and barriers to the use of this form of transportation. Therefore, this article seeks to answer the following research question: What are experiences of persons with disabilities in using paratransit services?

## Method

Theoretical framework (methodological orientation and theory)

This current study adopted a qualitative approach because of the limited scientific knowledge on the experience of persons with disabilities in using paratransit services. We explored the phenomenon using a constructivist view getting a deep understanding of multiple perspectives. <sup>18</sup> We used five focus group discussions for collecting valuable information through interaction and exchange about the experience of persons with disabilities. <sup>19,20</sup>

## Participant selection

We recruited participants following a sample schedule with criteria ("gender: female/male," "age," "place of living: rural, urban," "reasons for outdoor mobility limitations: wheelchair, pedestrian, vision, cognitive, or psychological impairments," "living situation: cared or independent," "relative of a person with disability," "use and non-use of driving services") to get a heterogenous group of participants.

We recruited participants via e-Mail or telephone through snowball sampling, contacting paratransit services, personal contacts to persons with disabilities, or gatekeepers in elderly homes, therapists, care and residential homes, or foundations. Potentially interested participants contacted the research team by e-mail or telephone. Since we did not reach person beyond the age of 84 years in the first recruitment phase, we contacted a residential home for reaching these persons. Thus, we organized a fifth focus group with people beyond the age of 80 years. After the drop out of five participants because of health (e.g., illness), technical issues (e.g., online focus group discussion), or not giving any reason, we included finally 27 participants with disabilities and 4 participants, which are people from the immediate environment of persons with disabilities (see Table 1). We classified the age and focus groups as follows: 25-43, 22-51, 58-84, 51-68, 84-100, because they shared akin experiences in using driving services and encourage each other in sharing their experiences. <sup>21,22</sup> We informed participants about the purpose of the study, the possibility of withdrawal at any time, the recording of the discussion and its deletion after the verbal transcription and ask them to sign a consent sheet.

## Data collection

We conducted the five focus group discussions between July and October 2021. The first four focus group discussions were carried out in July 2021. We used an online conference and meeting tool due to the COVID-19 pandemic as well as to the mobility difficulties of the participants. The research team instructed the participants in advance with written and oral instructions how to use the online tool and provided practice sessions. Other people received support from their therapists, social workers or relatives. To reach saturation, a fifth focus group took part physically in October 2021, in a quiet room of a rural care and residential home, where all five participants were residents. All interviews were conducted in Swiss German and audio recorded without disturbance. One researcher led the focus group as a moderator, following an open-end question, semi-structured discussion guide. We adjusted the discussion guide after the piloting and after receiving feedback of the steering group of the study, as well as after each focus group. Questions focused on participants' experiences with paratransit services, such as, for example: "tell us about your experience using the paratransit services the last time." Another person of the research team assisted as a supporting observer and by taking field notes. The focus groups lasted between 70 and 100 min.

## Data analysis

We transcribed the focus group interviews, in the interviewee's language Swiss German, based on the transcription rules by Creswell and Plano Clark<sup>18</sup> and analyzed the data using content analysis according to the description of Mayring<sup>1</sup> with the software MAXQDA 2020. We undertook the following steps: 1) Definition of the analysis unit and abstraction level, 2) inductive open coding because of the reduced prior theoretical knowledge and to keep the analysis naturalistic, 3) merging the codes to subcategories to support a summative understanding of the latent content, 4) definition of subcategory's in- and exclusion criteria, a coding example and a coding description. The subcategories showed structural similarities to the domains "environmental factors" and "activity and participation" of the International Classification of Functioning, Disability and Health (ICF).<sup>23</sup> Therefore, we moved from the inductive coding and sub-categorization approach to a deductive categorization according to these ICF domains. During the analysis, our epistemological assumptions were between the phenomenological and hermeneutic interpretation, staying close to the text in the coding process and subcategorization, and moving then more to a distant approach on a more abstract level, using some interpretation through the deductive categorization. To support trustworthiness, two researchers coded a part of a focus group interview independently and compared and discussed it afterwards. Finally, we sent the analysis with e-mail back to the participants for member checking and received two feedbacks. One concerned a spelling mistake, which we corrected and the other was an agreement on the content.

### Results

The participants experienced paratransit services as important to enable participation in different life areas. The use of paratransit services depends on various facilitating and hindering factors. Participants experiences could be allocated to the categories "activity and participation" and "environmental factors" with four and seven subcategories, respectively (overview see Table 2).

Activity and participation

Type of activities and frequency of use

Paratransit services are mostly used for short distances to medical consultations, leisure activities (e.g., meeting other people, singing) or daily duties (e.g., shopping, hairdresser). They are also

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**Table 1** Characteristics of participants.

Focus group	Number of participants	Age (mean/std)	Gender (Female)	Residence (urban)	Form of living (independent)	Relative	Mobility impairment
1	7	33.7/6.0	3	7	5	1	6/2/1
2	8	36.1/9.0	2	4	5	0	7/2/0
3	7	60.7/7.2	3	1	6	2	6/1/0
4	4	62.5/14.5	2	3	4	1	4/0/1
5	5	88.8/8.0	3	0	0	0	5/0/1
Total	31	56.36/20.16	13	15	20	4	28/5/3

Note. Following items are mutually exclusive: Gender (female and male); Residence (rural, urban); Form of living (independent, supervised). Mobility impairment includes three categories; physical/visual/cognitive.

helpful to get to activities in unknown circumstances and at night. For activities that require longer travel distances, participants prefer using other services (e.g., public transportation, private cars, special paratransit for long distances).

Changes in the state of health influence the use of paratransit (e.g., a decrease in health could increase the need of using paratransit) (see Table 2). Some people use the paratransit service always, some never. Those who indicated never using paratransit were able to use other transportation options (e.g., public or private

transportation, electric wheelchair). Other participants combine the paratransit services with different transportation options, depending on their health status, the type of activities they need or want to do, and the possibility of engaging in activities at home (e.g., in residential homes). The frequency of the use of paratransit varies between several times per day to once a month. Two participants indicated being very new to this situation of being dependent on paratransit services and have, therefore, a low frequency of use comparing to someone else, who is used to it since several years.

**Table 2**Results: Categories, subcategories, and quotes.

Category: Activity and participation						
Subcategories	Quotes					
Type of activities and frequency of use Saving time and energy	R: [without paratransit] So I would definitely, a lot of things I wouldn't do, that's the way it is" O: [When]]I'm invited [visiting my friends], then I have to say goodbye maybe twenty-five or half an hour earlier [if I take the train instead of the paratransit service].					
Experience of independency and normality	U: The problem is, you cannot travel self-determined. You have to be there at the right time [pick up train staff] and otherwise it doesn't work. And that's a problem for me. When I realize my self-determination is not guaranteed, then it pisses me off, actually. Z: I'm already dependent in my life on so many things, so I need help in the morning to get up, help in the evening to go to bed, to put on the jacket, actually, for everything. If I'm in a wheelchair, I manage quite well, or if I still have the public transportation, with which I can travel independently, then that's quite good. Yes, it's just the independence that I like very much. F: And it [using paratransit services] brought me back, let's say now, back into the normality of the world a little bit by being able to visit somebody. So not only because you have to go to the hospital or to the dentist but also purely privately, personally do something that does you good.					
Challenging change	A: «I'm no longer used to going away alone. For example, I used to go by car all the time. I have always been a convinced driver, of course, until the shutdown [stroke] I had []. Yes, if you can't do that [activity anymore, as you did before the stroke], then you just have to do something else [] And I have now found a good compromise.					
Category: Environmental factors						
Subcategories	Quotes					
Depending on support	E: That is very difficult, because I need support and this person has to stand around and wait, what is very unpleasant for me. I hate it even if someone has to wait for me somehow.  C: In our case, my husband has a lot of appointments at the hospital []. And I can't keep all the appointments myself, so I need the supplementary transportation service to bring him and fetch him again []. I can't manage that anymore.					
Experiencing safety	Q: I am afraid that I will suddenly find myself in a stalemate. Of course, I get stuck somewhere with the wheelchair, what am I going to do then? That's why I primarily prefer the paratransit services.					
Experiences with infrastructure and equipment	T: I need relatively large ramps so that I can drive up with my wheelchair. Both, with the electric wheelchair as well as with the active wheelchair and that went totally wrong the first time when I had to go [to a medical appointment]. They [paratransit services] came first with the small car, then with the electric lift, which also did not fit. In the end, they came with the big ramp but unfortunately the headrest was forgotten and then we stopped the exercise at this point.					
High costs pose challenge	E: Participation is directly related to funding, now in my case. [] Last year, I used up the subsidy's quota already in September and the money was not enough. And then I felt very excluded, or rather I was very dependent on external help.  O: The offers are always regionally limited. Someone who lives in [city] has no right to such subsidized rides in another canton. And that means that if I go to another canton to visit someone, then I don't have a card for subsidized transportation and pay the full price. [] there we are quickly at a very high sum.  F: I am entitled to eighteen trips per month. Last month when it was so nice weather, I needed four trips and then there are months in winter when I need more.					
Support, information, order and availability	B: You have to order the driving service early enough otherwise they are already fully booked. That means you also have to get the appointment at the hospital early enough. The coordination is also difficult with the waiting times of three to 4 h in the hospital.					
Influence of weather and climate	Y: I have trouble putting on a rain jacket and it gets difficult to move well [] and because of this, I take the paratransit services instead of driving with the wheelchair.  O: It is not possible to distinguish whether I'm on the street or the sidewalk [walking with a cane in snowy and icy weather], where does the sidewalk end, where does the street begin? All the road markings can no longer be felt, and that is of course a huge risk, and in such cases paratransit is important.					
Living environment and accessibility	Z: In earlier times, there was no [accessible] public transportation, I traveled with my own car or with the paratransit service and this became very expensive. This is [] the reason why I moved into town.					

Note. Selection of quotes given by participants during the focus group discussion.

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#### Saving time and energy

Participants indicated saving time and energy when using paratransit. To start with, valuable time is saved for dressing (e.g., don't need to wear a jacket), moving from home to the closest stop of public transport, and the journey itself. One participant, for example, experienced that his impairment and dependencies on other persons in activities (e.g., in self-care) decreased his use of time, which was a burden. Therefore, the use of paratransit was valuable because of an increased and saved time comparing to public transport (see Table 2). The use of public transportation is associated with missing connections, cancelations, and delays. Moreover, planning the use of public transportation (e.g., organizing support of staff) required a lot of effort. In contrast, organizing and using paratransit was perceived as easy and convenient, and therefore saved him energy.

## Experience of independency and normality

Some participants prefer using public transportation compared to paratransit services, because of the experience being part of the society and being able to travel with others in the same vehicle. In addition, they wanted to or show society, that persons with disabilities are also part of them. Participants mentioned the difficulty traveling with others (e.g., friends, family members), especially if more than one person uses a wheelchair. Most participants stressed the importance of "normality" in terms of being independent in time and choice of transportation. Some participants experience "normality" and "independency" in using paratransit services, others more in taking a private car or public transportation (see Table 2). However, they have in common that the more they depend on others, the more they feel restricted in self-determination, which influences their well-being (see Table 2).

## Challenging change

The results of this study revealed that the participants experienced changes in their health status (e.g., after stroke) and subsequent restrictions (e.g., in the life and mobility) as challenging. One participant, for example, a passionate car driver, was suddenly dependent on driving services of his wife which reduced his participation in other areas of life (e.g., leisure activities) (see Table 2). Other participants, who are dependent on paratransit services expressed similar experiences. They seem to have in common that recent change situations come along with higher challenges and dissatisfaction in using paratransit (i.e., it takes some time to getting used to the new situation and some time to reorganize one's mobility). However, a topic concerning most participants was that if they would have any possibility and free choice of using transportation, they would most appreciate the new won spontaneity.

## Environmental factors

## Depending on support

Persons who provide support to the participants are family, friends, personnel of paratransit or employees of public transportation services. The ways they provide support are diverse and include, for example, pushing wheelchairs, escorting individuals on public transportation, or providing private transportation. The need of support has different dimensions within participants (see Table 2). More specifically, some participants need total (i.e., one-to-one) support in most life areas, (e.g., due to low vision) whereas others only need support for using transportation. Paratransit services are experienced as helpful for an independent mobility or to reduce the burden on caregivers (e.g., driving a husband with impairment). However, depending on support is connected to negative experiences such as discomfort (e.g., when

another person needs to wait) or uncertainty (e.g., not knowing for sure about the availability of support from staff of public transportation) and additional costs (e.g., for hiring a person to provide support in public or the use of paratransit transportation).

## Experiencing safety

Safety is an issue experienced as a facilitator in using paratransit. Participants appreciate the safety precautions taken by paratransit providers in comparison to public transportation. A further safety advantage is seen in the use of paratransit in times of epidemic situations because participants are not exposed to the commuter flow of public transportation. But safety is also mentioned by the participants in being sure to get to the right location at the right time (see Table 2).

### Experiences with infrastructure and equipment

Overall, participants are satisfied with the given infrastructure (e.g., fixation systems for wheelchairs in vans) and equipment (e.g., ramps) of the paratransit services. A few participants experienced the infrastructure and equipment as barriers (e.g., car is labeled with disabled transport or is not accessible with wheelchairs) (see Table 2). Moreover, there seems to be no standard infrastructure and equipment for paratransit services. This requires extra effort from users to collect crucial information and plan ahead of time (e.g., assuring that there are large ramps available for heavy wheelchairs).

#### High costs pose challenge

Participants in this study experienced costs of paratransit as an important factor for participation in different life areas. Costs and financial support for paratransit services vary within Switzerland for different reasons such as non-standardized prices between different paratransit providers (in certain areas combined with monopoly positions), unclear benefits of the social security system and limited availability of subsidized rides. Participants mentioned the availability of financial support from different foundations (e.g., contingents, fixed amount, or total cost absorption). Participants experience the subsidies, especially for leisure time activities, as very supportive and express that they could not afford paratransit's without them. They ration their allotted number of rides per month according to environmental factors, such as weather conditions. For most participants the number of subsidized rides is sufficient for the number of activities during a year. However, others indicated being forced to reduce activities due to lack of transportation. Some subsidies are restricted to one canton only, meaning that as soon as participants cross the border to another canton, the costs for the out-of-canton-leg of the trip increase tremendously. This is experienced as a restriction and barrier for participation in everyday life (see Table 2). Others have had the opportunity to hold a paid position and to earn enough money to afford also rides outside the subsidized trips of the paratransit services.

Participants indicated difficulties obtaining information on available financial support for paratransit services. Benefits depend on each individual situation and regional regulations. Although most participants experience paratransit as too expensive, there are also participants who experience the costs of paratransit services not as restriction to their participation in activities. Some older participants compared the costs of the paratransit services to owning a car and find them comparable. They see paratransit services as a valid substitute for owning a car. Another person even estimated the service as being too cheap. This person felt that drivers are underpaid for their work. Participants talk of different options for how to handle this financial issue and found solutions (e.g., invite friends at home). Nearly all participants mentioned the need of having a unified system within Switzerland to use

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paratransit services at the same costs as public transportation and not being restricted to cantonal boundaries.

Support, information, order, and availability

Overall, paratransit providers are experienced as supportive and friendly (e.g., by providing support with getting dressed, carrying luggage, transferring into the car, personal support of persons with cognitive impairments). However, participants experienced challenges in accessing information about transportation options, especially those being in a new mobility situation due to changing or new impairments (e.g., how, and where information can be accessed). Health professionals (e.g., general practitioner) were experienced as facilitators for accessing information.

In general, the availability of paratransit services improved over the last years in Switzerland, but there are still differences among the cantons (e.g., number of providers, ability to transport wheelchairs, availability of paratransit at night or in pandemic situation). Even the above-mentioned efforts required to plan each trip ahead of time differ from canton to canton, in some places, transportation is available within the hour, in other regions, users are required to book 24 h in advance (see Table 2). The coordination of medical appointments and the corresponding paratransit service is experienced as challenge. In conclusion, although participants experienced barriers in the organization of paratransit and difficulties in receiving information, overall, they valued the good paratransit service.

#### Influence of weather and climate

The results of the study revealed that the environmental factor "weather and climate" was experienced as a further facilitator or barrier for using paratransit services (see Table 2). To start with barriers, good weather did decrease the use of paratransit services because participants were able to use alternative transport vehicles for short distances (e.g., powered wheelchair or towing device), or were able to walk. In the opposite, rain, cold weather, or snow increased the use of paratransit services. One participant, for example, experienced increased spasticity in the cold, leading to reduced mobility and, therefore, choosing paratransit services. Another participant with visual impairment expressed difficulties using his cane efficiently in snowy/icy conditions, and therefore used paratransit services more often during the winter. Overall, changing weather conditions seem to require spontaneous decisions in relation to the use of transport services. Furthermore, the frequency of use of paratransit services and with it the amount of (subsidized) rides needed is strongly influenced by the weather. If there are many rainy days in summertime, participants do not have enough allotted rides in the wintertime. In conclusion, weather and climate is experienced as a facilitating and hindering factor in using paratransit.

### Living environment and accessibility

We found that participants experienced their living environment, including the access to transport services, as important. Although, the access to transportation in rural areas improved during the last years, it is experienced to still be limited (see Table 2). However, there are participants for which the living environment is neither a supportive nor hindering factor with regards to the use of transportation. For example, one participant with visual and walking impairment needs paratransit services for every trip and experienced that the living environment has no impact on this situation.

Some participants mention that their use of paratransit services was reduced in reaction to an improved accessibility of public transportation and open spaces in their living environment. However, while accessibility has improved, there is still room for further

ameliorations in this regard. However, some participants, due to the severity of their impairments, will remain dependent on paratransit services, even if current accessibility guidelines are fully met by public transport providers.

#### Discussion

The experiences of the participants nicely reflect, similar as demonstrated by the ICF model, the influence, and dependencies of different supportive and hindering factors (e.g., environmental factors, activities and participation, body functions & structures and personal factors) for the use of paratransit services. The cost of paratransit services restrict people's participation in life in three ways, in particular: when all alloted subsidized yearly rides are used, when rides cross cantonal borders, or when the individual lacks information about how to obtain financial support. Participants must ration and prioritize their rides, also dependent on the weather condition.

The persons most affected by limited access to paratransit services are those with low income. In Switzerland, 27.8% of persons with disabilities are at risk of poverty in comparison to 10.3% of the whole population.<sup>24</sup> These people have difficulties to co-pay or pay for rides themselves if they have used up all allotted subsidized rides. This leads to transport poverty.<sup>25</sup> Transport poverty is the combination of transport disadvantage (e.g., missing information, high costs, poor service coordination) and social disadvantage (e.g., low income, low skills, ill-health) and can lead to social exclusion since people experience inaccessibility to different life areas (e.g., services, social networks, goods, decision-making).<sup>25</sup> Furthermore, transport poverty negatively influences people's well-being. <sup>26,27</sup> In our study, some participants expressed the influence of the transportation disadvantages on their well-being such as feeling excluded from society or feeling dependent and inflexible. Other participants seemingly adjusted to their current situation in changing to activities which are feasible (e.g., inviting friends to their home) or accepted a reduction in participation possibilities. An association between social participation, paratransit services and well-being was also found by Levasseur et al. and Blais & El-Geneidy.<sup>28</sup>

The results of this study show that participants would use the paratransit services more, if no restriction (e.g., paratransit availability, infrastructure, coordination, costs) would exist. Also, they would prefer to have more flexibility and spontaneity, self-determination, and autonomy. According to Murray<sup>29</sup> persons with disabilities experience a decreased autonomy in relation to transportation than persons without disabilities. Although literature on the influence of self-determination on well-being in the context of transportation is rare, the overall influence of self-determination on well-being is described by the self-determination theory. Therefore, according to this theory, we assume that limited self-determination in using transportation influences the well-being of persons with disabilities.

The Swiss Federal Office of Statistics<sup>31</sup> describes an increase in inter-cantonal journeys of the general Swiss population over the last decade. Whereas for public transport, nation-wide tickets can easily be purchased with one click, pricing for paratransit services can change at cantonal borders. These differences increase inequality between those depending on paratransit services and the general population, due to the experienced lack of paratransit coordination between the cantons of Switzerland.

Policymakers worldwide, already acknowledge the involuntary transportation disadvantage and steps are made towards more inclusive transportation options. However, further investments are needed to implement the CRPD in the use of transportation, especially concerning the increased demand on paratransit due to

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the aging population. The results of this study are a basis for policymakers in Switzerland for implementing further guidelines and actions in favor for persons with and without disabilities.

This study has some limitations. The results reflect participants experiences of only one part of Switzerland. Because the situation of paratransit services differs between cantons in Switzerland. further studies are needed. The number of persons beyond the age of 65 in this study comparing to the number of people in this age group using paratransit is small. In further investigations it is important to include more older people from diverse living settings to get a good representation of peoples' experiences in using paratransit services.

## **Conclusions**

Participants' use and experiences with paratransit is highly individual. The federalist system in Switzerland supports a local and cultural embedment as well as, to some extent, the possibility of users to have a say in paratransit offers. Because of the relatively small size of Swiss cantons, transportation needs of people often go beyond the cantonal boarders, which results in difficulties (e.g., financing). The resulting drawbacks are experienced by the participants in limitations to carry out meaningful activities. The outcome of this study underpins the need of coherent guidelines for paratransit providers and legal integration (e.g., equal transportation rights, clearly defined financial and support systems) leaving at the same time enough flexibility, adjustability and individuality to the paratransit providers with regards to the needs of their customers.

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## **Conflicts of interest**

This manuscript is not under review elsewhere, the primary data has not been published previously, and is not accepted for publication. We have no conflict of interest to disclose.

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