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# Committee on the Rights of Persons with Disabilities

# Views adopted by the Committee under article 5 of the Optional Protocol, concerning communication No. 46/2018\*, \*\*

Communication submitted by: S.K. (represented by counsel, Jukka

Kumpuvuori)

Alleged victim: The author

State party: Finland

Date of communication: 7 February 2018 (initial submission)

Document references: Decision taken pursuant to rule 70 of the

Committee's rules of procedure, transmitted to the State party on 27 February 2018 (not issued

in document form)

Date of adoption of Views: 24 March 2022

Subject matter: Personal assistance

Procedural issues: Exhaustion of domestic remedies; lack of

substantiation of claims

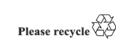
Substantive issues: Discrimination on the grounds of disability; right

to liberty; living independently and being

included in the community

Articles of the Convention: 5, 14 and 19
Article of the Optional Protocol: 2 (d)–(f)

1. The author of the communication is S.K., a national of Finland born on 8 January 1982. He claims to be a victim of violations by the State party of articles 5, 14 and 19 of the Convention. The Optional Protocol entered into force for the State party on 10 June 2016. The author is represented by counsel.





<sup>\*</sup> Adopted by the Committee at its twenty-sixth session (7–25 March 2022).

<sup>\*\*</sup> The following members of the Committee participated in the consideration of the communication: Rosa Idalia Aldana Salguero, Danlami Umaru Basharu, Gerel Dondovdorj, Gertrude Oforiwa Fefoame, Vivian Fernández de Torrijos, Mara Cristina Gabrilli, Amalia Eva Gamio Ríos, Samuel Njuguna Kabue, Rosemary Kayess, Kim Mi Yeon, Abdelmajid Makni, Sir Robert Martin, Floyd Morris, Jonas Ruskus, Markus Schefer and Saowalak Thongkuay.

<sup>&</sup>lt;sup>1</sup> The author has requested anonymity.

## A. Summary of the information and arguments submitted by the parties

#### Facts as submitted by the author

- 2.1 The author has physical and intellectual disabilities. He needs assistance in all daily activities. According to medical reports, the author cannot be accommodated in a group residence, and for independent living he needs a personal assistant 24 hours a day.
- 2.2 Personal assistance was introduced in the State party's legal system in 1987 through the Disability Services Act (No. 380/1987). At that time, the only way of organizing personal assistance was for persons with disabilities, or their families, to employ a personal assistant. The personal assistant system was reformed in 2009. One reason for the reform was that the duty of a personal assistant to act as a private employee had restricted the enjoyment of the service by persons with disabilities. It was argued that the new service would also provide support for persons with complex needs and high support requirements. Different forms of personal assistance services were introduced, enabling provision of the service without the obligation to function as an employee. After the reform of the Disability Services Act in 2009, there were three ways in which personal assistance could be arranged: (a) persons with disabilities could be compensated for the necessary and reasonable costs of recruiting an assistant; the municipality might also, in practice, undertake to pay the assistant's wage and fulfil the other employer obligations, but the person or family would remain the employer; (b) persons with disabilities could be provided with service vouchers; or (c) the services could be provided by the municipality or purchased from private or public service providers. According to the Act as amended in 2009, in order to receive personal assistance, persons with disabilities must have the resources to define the content of the personal assistance and the modalities for providing it (referred to as the "resources criterion").<sup>2</sup> The author clarifies that the term "resources" intended to refer not to monetary resources, but to the capacity of a person to define the content of personal assistance.
- 2.3 The 2009 reform has later been explained by the State party's Ministry of Social Affairs and Health to have been only partial because the resources criterion remained. However, it was argued that the introduction of this criterion had limited the accessibility of personal assistance to some persons with disabilities, particularly persons with cognitive impairments. The Supreme Administrative Court's interpretation has been restrictive, especially with regard to the provision of personal assistance to enable persons with intellectual disabilities to live in their own home, while it has considered personal assistance suitable for activities outside of the home. Municipalities' interpretations have been similar or even more restrictive. The deletion of the resources criterion was proposed by the previous Government, but the current Government wishes to maintain it. Civil society organizations strongly and almost unanimously demand the deletion of the resources criterion.
- 2.4 On 1 January 2014, the author rented an apartment so that he could live independently in his own home. The same year, he applied for personal assistance for 140 hours per week in accordance with the Disability Services Act, to be able to live independently. The plan was that the author would live in his own home initially with personal assistance and the help of his parents and thereafter with only personal assistance.
- 2.5 On 2 October 2015, an official of the Basic Security Division of Kirkkonummi municipality granted the author personal assistance for 60 hours per week, for independent activity outside his home, which was against his plan to live independently with personal assistance in his own home. In a decision of 11 November 2015, the Basic Security Unit of the Basic Security Division of Kirkkonummi municipality upheld the official's decision.
- 2.6 On 26 May 2016, Helsinki Administrative Court dismissed the author's complaint against the decision of the Basic Security Division. The Court referred to a 2008 report of the Social Affairs and Health Committee, in which it was stated that a prerequisite for receiving personal assistance was that the person in need of help must have the resources to define the content of the assistance and the modalities for providing it, but that that requirement

<sup>&</sup>lt;sup>2</sup> Section 8 c (2) of the Disability Services Act provides that the purpose of personal assistance is to assist a person with a "severe" disability to make his or her own choices in everyday activities, work and studies, hobbies, social participation and the maintenance of social interaction.

excluded persons with disabilities who, according to an assessment carried out by a third party, were unable to define their need for assistance themselves. It was further stated in the report that, in most cases, the need for assistance was mainly based on care, treatment and surveillance, which should be accommodated by means other than personal assistance.

- Helsinki Administrative Court mentioned in its decision that the author needed help with all his daily tasks and with moving; that he communicated through gestures, expressions and single words; and that he participated in household tasks to a certain extent, but the documents provided did not demonstrate that he would have the initiative to perform the tasks himself, and he must be reminded and encouraged in that regard. The Court considered that, since personal assistance was intended to support the choices of persons with "severe" disabilities and their ability to live independently, the person must be able to define the content of the assistance and the way in which it is implemented themselves; this definition cannot be based on another person's opinions. The Court revealed that, according to the medical reports in his file,3 the author has the ability to express his needs in everyday situations, but not to determine the content and modalities of the assistance that he would need to live in his own house. In the view of the Basic Security Division, since the author lacked the resources to define his need for assistance and the way in which it should be implemented, he could therefore not be granted the full 140 hours of personal assistance per week. The Court upheld the Division's decision to grant the author 60 hours of personal assistance per week, mainly to enable him to carry out independent activities outside the house and to get ready for these activities.
- 2.8 The author appealed the decision of Helsinki Administrative Court, noting that it did not explain what kind of ability to define the content of the assistance and the modalities for providing it was required in order to receive the personal assistance necessary to live in one's own home. He invoked article 19 of the Convention, submitting that States parties recognized the equal right of all persons with disabilities to live in the community, with choices equal to others, and that it should also be possible to arrange the living of persons with disabilities in their own homes with the help of personal assistance.
- 2.9 On 14 June 2017, the Supreme Administrative Court dismissed the author's appeal. It held that while the author possessed the ability to express his needs in everyday situations, it had not been demonstrated that he had the resources to define the content of the assistance and the manner its implementation, which was necessary in the case of personal assistance for the purposes of living independently in one's own home. The Court considered that the fact that the author had previously been able to use personal assistance at home did not create a legitimate expectation that he should automatically be granted personal assistance in compliance with section 6 of the Administrative Procedure Act. It also considered that national and international rules and regulations did not provide the author with the specific right to a personal assistant at home while he did not comply with the requirements of section 8 c (2) of the Disability Services Act.
- 2.10 Eventually, the author moved back with his parents, because they were unable to move in with him in his own house to provide him with round-the-clock assistance.

#### Complaint

3.1 Invoking the Committee's general comment No. 5 (2017), the author complains under article 19 of the Convention that he has been denied his personal and individual choice and control across the key areas of his life. He has been presumed to be unable to live independently in his own home with the help of personal assistance. The support given to him is in practice tied to particular living arrangements. Resources are invested not in individually planned services, but rather in institution-like services. The municipality and the State party have refrained from providing suitable welfare services that would enable him to

<sup>&</sup>lt;sup>3</sup> The medical reports consisted of the following: statements given by a health-centre physician on 8 September 2014 and 16 December 2015; a statement given by a specialist in neurology on 28 November 2014; a statement given by the ward physician of a clinic of physiatrists on 17 April 2015; reports dated 10 January 2014 and 1 February 2014 by the author's personal assistants; a physiotherapist's report dated 7 August 2015; and a report on a visit to the author's home on 18 September 2015.

live independently in the community, which, in his case, has led to dependence on his family, isolation and segregation.

- 3.2 The author claims that because of the lack of adequate personal assistance, he is unable to live his own life with his own daily schedule and routines, and is always obliged to adapt and follow the routines of his family members. Yet, informal help from his parents is the only way to keep him away from institution-like settings, which are not compatible with his personal needs and would very quickly lead to a deterioration in his well-being. Furthermore, article 19 of the Convention does not permit any form of institutional support services, because of the associated segregation and limitation of personal autonomy. The institutionalization of the author would therefore amount to a violation of article 19. Should the informal support of the family members come to an end, the author's institutionalization would be the only option left, under the State party's interpretation of the legislation. For the time being, the violation results from the fact that assistance to the author should not have to be provided informally by his family.
- 3.3 The author further submits that the State party is in violation of the Convention because the authorities have not adopted a human rights-based approach in assessing his need for personal assistance, but have instead adopted a medical approach regarding the author's impairment. Had it not been for the support of his parents, he would have been forced to move to an institutional setting.
- 3.4 The author considers that article 5 of the Convention has also been violated, in conjunction with article 19. Statistics from civil society organizations show that persons with intellectual impairments live with their parents even when adults. There is a significant lack of community services for persons with intellectual disabilities that comply with the requirements of article 19 of the Convention. The current practice therefore amounts to a violation of the principles of equality and non-discrimination. The criterion that persons with disabilities must have the resources to define the content of the personal assistance and the modalities for providing it, as contained in the Disability Services Act, is discriminatory in the author's case, but also against persons with intellectual disabilities in general. According to the author, persons with other forms of disabilities are more eligible for personal assistance than persons with intellectual disabilities, because the criterion affects only persons with intellectual disabilities.
- 3.5 Lastly, the author claims a violation of article 14, given that no support is available to him in the community. If his parents were not helping him, the author would be forced to live in an institution-like setting, which would not cater for his personal needs and would not allow him to choose where and with whom to live.
- 3.6 As to the admissibility *ratione temporis* of his complaints, the author contends that the violations have continued until after the entry into force of the Convention and the Optional Protocol thereto for the State party, on 10 June 2016.<sup>4</sup> He notes that the decision of the Supreme Administrative Court, which cannot be dissociated from the lower courts' decisions, has and which examined his right to personal assistance, was handed down after the entry into force of the Convention and the Optional Protocol thereto.

#### State party's observations on admissibility and the merits

4.1 On 27 April 2018 and 27 August 2018, the State party submitted its observations on admissibility and the merits. While admitting that the communication is admissible *ratione temporis*, the State party considers that it is not for the Committee to review the facts or the application of domestic legislation in the case in question, and that the author has failed to substantiate, for the purposes of admissibility, his claim that the conduct of the authorities amounted to arbitrariness or denial of justice. It argues that the author has only indirectly raised his claim under article 5 of the Convention in domestic proceedings, and that he has not raised his claim under article 14 of the Convention at all, which amounts to non-exhaustion of domestic remedies. It adds that the author is essentially raising a hypothetical

<sup>&</sup>lt;sup>4</sup> The author cites the Committee's Views in *Jungelin v. Sweden* (CRPD/C/12/D/5/2011).

violation of article 14, because he has not further substantiated his claim that this provision has been violated and because the author has not been deprived of his liberty in any way.

- 4.2 As to the merits, the State party points out that article 19 of the Convention does not require that States parties ensure the right of persons with disabilities to live independently specifically by means of the type of personal assistance referred to in the Disability Services Act, but requires that they ensure that persons with disabilities have access to a range of inhome, residential and other community support services, including personal assistance. It notes that the purpose of personal assistance is to support the personal choices that is, the right to self-determination of persons with disabilities. That purpose cannot be fulfilled if the person with disabilities is unable to make his or her own choices, even when supported. In such cases, the person's needs can be served better and more safely by means of other services. The condition concerning resources therefore safeguards the person's right to self-determination and protects the person from abuse of his or her mental and physical integrity.
- 4.3 The State party considers that while doctors may take a stand on a person's need for assistance, the determination of the most suitable service to support the person to live independently cannot rest only on a doctor's assessment. According to a report received by the National Supervisory Authority for Welfare and Health, service housing under the Disability Services Act was proposed to the author's guardian as an alternative service for the author. Service housing consists of a dwelling and residential services necessary for the client to cope with daily life. Residential services may include assistance in activities related to habitation, such as moving, getting dressed, maintaining personal hygiene, taking one's meals and cleaning, as well as services needed to promote the recipient's health, rehabilitation and well-being. The Act does not define where and how the service housing should be organized. Residential services related to service housing may be provided at the client's home, whether rented or owned.
- 4.4 The State party declares that it has been unable to ascertain whether there has been a misunderstanding that may have given the author's guardian the impression that service housing cannot be provided in the author's own home, such as individual services provided by the service provider so that the assistants remain the same. However, this does not imply that the author's case would have been decided differently. The State party also notes that the author has not explored alternative services.
- 4.5 As to the alleged violation of article 5 of the Convention, the State party highlights that the Disability Services Act contains no definition, categorization or other factor that would place anyone in a position of inequality as a result of a diagnosis. Assessment of whether a person with disabilities meets the requirement of having the resources to define the content of the personal assistance and the modalities for providing it is done on the basis of the person's individual situation, needs and abilities, not the person's diagnosis or type of disability.

#### Author's comments on the State party's observations on admissibility and the merits

- 5.1 On 30 May 2018 and 24 December 2018, the author submitted comments on the State party's observations. He insists that he is not arguing that the Disability Services Act has been incorrectly interpreted or applied as a matter of domestic law, but rather that its interpretation and application contradict the requirements of the Convention because the domestic courts have not taken into account the provisions of the Convention. He further reiterates that the personal assistance system hinders the right of persons with intellectual disabilities in particular to live independently and that the eligibility criteria are discriminatory.
- 5.2 As to the State party's allegation that he has not raised his claim under article 14 of the Convention in domestic proceedings, the author clarifies that in one of his submissions to the Supreme Administrative Court, he included a publication that made references to the

<sup>&</sup>lt;sup>5</sup> The State party notes that the Committee has previously found – in *H.M. v. Sweden* (CRPD/C/7/D/3/2011), para. 8.9, and *Bacher v. Austria* (CRPD/C/19/D/26/2014), para. 10 (a) (i) – that other options are indeed available, illustrating that in-home personal assistance is not the only option that could support the author in living independently and being included in the community.

claim that the right to live in the community is closely linked to fundamental rights such as the right to personal liberty. He also argued in that submission that the restriction of personal assistance to activities outside the author's own home violated the right to personal liberty and the right to privacy, as guaranteed by the Constitution, the Convention and the Convention for the Protection of Human Rights and Fundamental Freedoms. The author therefore considers that he did raise article 14 of the Convention in domestic proceedings. He also submits – referring to his claim under article 5 of the Convention – that indirect reference to Convention standards should suffice.

- 5.3 As to the merits, the author reiterates that the State party's legislation denies personal assistance for people who need support in their decision-making. He finds it illogical and unlawful that he was recognized to have the resources to define the content of the assistance and the modalities for providing it outside his home and when preparing for activities outside his home, but that he was judged not to have such resources with respect to the in-home assistance that he needs. It is still unclear what type of resources are enough to meet resources criterion for in-home assistance.
- 5.4 The author considers that the State party's argument that the condition concerning resources safeguards the person's right to self-determination is contradictory and not supported by the Convention. He insists that the resources criterion is discriminatory because it can be met only by persons who can make independent decisions about assistance, and therefore not by, for example, persons with intellectual disabilities.
- 5.5 The author contests the State party's statement that service housing was proposed to him. He is not aware of any proceedings, records or reports of the National Supervisory Authority for Welfare and Health. There have been no decisions on service housing for the author, and the municipality has not offered him this service. In the administrative decision of 11 November 2015, it is mentioned only that the municipality suggested that the author's mother apply for service housing. However, the author declares that the State party has not demonstrated that service housing would be an alternative to round-the-clock personal assistance for persons with intellectual disabilities. Such personal assistance is available for persons with other type of disabilities, but not for those with intellectual disabilities because of the artificial and discriminatory resources criterion.
- 5.6 According to the author, the State party has not given any examples of cases in which independent living has been facilitated for persons with an intellectual disabilities in their own apartment, because such cases seem not to exist. However, there are cases where such an arrangement has been possible for persons with other types of disabilities; that is, those persons who "have the resources". The State party does not explain why the author would not need a service that would allow him to live independently. In conclusion, as a consequence of the resources criterion in the State party's legislation, the author is able to enjoy the rights under article 19 of the Convention outside his home, but not inside his home.
- 5.7 As to article 5 of the Convention, the author points to the State party's statement that persons without sufficient decision-making "resources" cannot secure personal assistance, which represents a form of categorization that is disadvantageous for the author. Thus, discriminatory categorization does exist and, in this sense, the author recalls that the previous Government was of the view that the resources criterion was discriminatory in nature.
- 5.8 Lastly, as to article 14 of the Convention, the author recalls that the State party has an obligation to prevent deprivation of liberty. He explains that if he is not provided with personal assistance, he will be forced either to live with his parents or to move to a care home or institution, which represents deprivation of liberty.

<sup>&</sup>lt;sup>6</sup> Council of Europe, Commissioner for Human Rights, *The Right of People with Disabilities to Live Independently and Be Included in the Community* (Strasbourg, 2012).

The author clarifies that there are two types of personal assistance under the State party's law: the personal assistance itself, subject to the resources criterion, and personal assistance as part of service housing, not subject to the resources criterion.

#### State party's additional observations

- On 8 March 2019 and 28 August 2019, the State party reiterated its previous observations, recalling that the Convention does not oblige it to provide the author with personal assistance under section 8 c of the Disability Services Act, but requires it to provide him with access to a sufficient range of services to support living and inclusion in the community and to prevent isolation and segregation. The fact of the legal criteria for personal assistance not being met does not prevent a person with disability from living independently. The State party disagrees with the author's suggestion that no service other than personal assistance would allow him to live independently. It reiterates that independent living can be facilitated for persons with disabilities in the form of service housing, as defined in the Disability Services Act, in an apartment either owned or rented by the person involved. The services needed at home can be customized and provided by a permanent team of carers, for example, and they can be adapted for round-the-clock service requirements. Alternatively, service housing can be provided for a person in a suitable housing unit in which the requirements for specific services are duly taken into account. In such a case, the person involved takes possession of the rented apartment subject to all the regular rights and obligations of a tenant, and staff provide the services necessary for coping on a daily basis. The State party reiterates that service housing as defined in the Disability Services Act was proposed to the author's guardian as an optional service.
- 6.2 For the State party, the right to access individualized, assessed support services is an economic, social and cultural right. The obligation of States parties under the Convention is to take measures to progressively realize these rights, and to act consistently with the obligations that are immediately applicable. Article 19 of the Convention does not require States parties to provide all individuals with whatever form of arrangements that they consider preferable.
- 6.3 The State party submits that, as of November 2018, the author declined all other services as an alternative to the personal assistance that he had requested. His guardian was not willing to accept the alternative services proposed by the municipality.
- 6.4 The State party also provides information on the ongoing domestic reform of the legislation on disability services. During the consultation process held in the summer of 2017, it was considered important that personal assistance continue to be determined by the persons with disabilities themselves. While many of the parties involved in the consultations were indeed of the opinion that the retention of the resources criterion in the law would undermine equality among persons with disabilities, others held that the resources criterion was needed in order to ensure that the provision of personal assistance remained a service that contributed to the right of self-determination of the person concerned. After an overall assessment, in which the strengths and weaknesses of the resources criterion were balanced, its underlying aims considered and the views presented during the consultation process taken into account, it is now being proposed to maintain the resources criterion in the legislation.
- 6.5 The State party further clarifies that the resources criterion under the Disability Services Act does not mean that a person with disabilities would need to be able to determine the content of the assistance and the modalities for providing it entirely independently. Such determination may be made with the support of another person or by using various communication aids. Consequently, it is enough that the person possesses "some resources" that may be activated by the support provided by another person or a communication aid. This has been confirmed on several occasions by the Supreme Administrative Court. Thus, although the resources criterion can be met in situations in which the content of the assistance and the modalities for providing it are determined with support, the national authorities did not in the author's specific situation find that he met the resources criterion. The author's

<sup>&</sup>lt;sup>8</sup> The other services offered consist of the following: transport services, consisting of 18 free trips per month outside regular working hours; personal assistance pursuant to the Disability Services Act; and day activities pursuant to the Act on Special Care for Persons with Intellectual Disabilities three days per week, including travel to the day centre and back.

The State party refers to two decisions handed down by the Supreme Administrative Court on 12 August 2011.

mere disagreement with the domestic court's decision does not in itself imply a violation of the Convention.

6.6 As to the author's allegation of discrimination, the State party emphasizes that the resources criterion does not make any distinction, exclusion or restriction based on disability as such, nor does it have the effect of depriving those who do not meet it of the possibility of living independently and being included in the community by other means.

#### Author's comments on the State party's additional observations

- 7.1 On 7 April 2019 and 25 September 2019, the author submitted additional comments. He insists that any service other than personal assistance would not allow him to live independently. The current assistance provided by his parents as informal carers has been the only means for the author to avoid living in an institution-like setting. While admitting that article 19 of the Convention does not require any specific service to be provided, but rather a range of services, the author holds that if he needs personal assistance only, then that is the service that must be provided to him. The State party cannot discharge this obligation by providing him another service, which is insufficient to guarantee that he can live independently. The services necessary must be provided without requiring him to move to an institution.
- 7.2 Following the State party's statements that service housing would constitute an alternative service, the author's counsel contacted the Ministry of Social Affairs and Health. The Ministry was not able to provide information on the existence of round-the-clock solutions for persons with intellectual disabilities in their own apartment. Such a service is therefore only theoretical. As to the State party's statement that service housing was proposed to the author's guardian, the author denies that any proposals were made that would enable him to live in his own apartment and receive assistance there.

## B. Issues and proceedings before the Committee

### Consideration of admissibility

- 8.1 Before considering any claim contained in a communication, the Committee must decide, in accordance with article 2 of the Optional Protocol and rule 65 of its rules of procedure, whether the communication is admissible under the Optional Protocol.
- 8.2 The Committee has ascertained, as required under article 2 (c) of the Optional Protocol, that the same matter has not already been examined by the Committee, and that it has not been, nor is it being, examined under another procedure of international investigation or settlement.
- 8.3 The Committee notes the author's claims that the decision of the Supreme Administrative Court, which cannot be dissociated from the lower courts' decisions, and which examined his right to personal assistance, was handed down after the entry into force of the Optional Protocol for the State party. It also notes that the State party does not contest the competence *ratione temporis* of the Committee to address the author's complaint. The Committee therefore considers that it is not precluded by article 2 (f) of the Optional Protocol from examining the present communication.
- 8.4 The Committee notes the State party's argument that the author's complaints under articles 5 and 14 of the Convention should be found inadmissible under article 2 (d) of the Optional Protocol on the grounds of non-exhaustion of all available domestic remedies, although it does admit that the author has indirectly raised his claim under article 5 in domestic proceedings. The Committee notes the author's statement that indirect reference to article 5 should be enough and that he did make reference to his right to liberty under article

In its observations of 28 August 2019, the State party notes that the Ministry does not keep registers or other statistics on decisions made regarding persons with disabilities as clients of municipal services or on persons receiving such services.

- 14. Accordingly, it considers that the author has exhausted domestic remedies for the purposes of article 2 (d) of the Optional Protocol.
- 8.5 As regards the author's claims under article 14 of the Convention, the Committee notes the author's argument that in the absence of personal assistance, he is forced either to live with his parents or to move to a care institution, which represents deprivation of liberty. However, the Committee also notes that these allegations are submitted in general terms, and that the author has never been deprived of his liberty in the sense of article 14, which relates to any form of detention or institutionalization of persons with disabilities.<sup>11</sup> The Committee therefore considers that this part of the communication is inadmissible for lack of substantiation, under article 2 (e) of the Optional Protocol.<sup>12</sup>
- 8.6 There being no other obstacles to admissibility, the Committee declares the communication admissible and proceeds with its consideration of the merits.

#### Consideration of the merits

- 9.1 The Committee has considered the communication in the light of all the information that it has received, in accordance with article 5 of the Optional Protocol and rule 73 (1) of its rules of procedure.
- 9.2 The Committee first notes the author's claim that, in the absence of in-home personal assistance, he is not able to exercise his freedom of choice to live independently, and that he therefore needs to depend on his parents' support to avoid entering a specialized health-care institution because the State party does not provide him with suitable personal assistance that would enable him to live independently in the community. In this regard, the Committee recalls that living independently and being included in the community, as reflected under article 19 of the Convention, means exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society. 13 Article 19 (b) of the Convention requires that States parties take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of their equal right to live in the community, with choices equal to others, and their full inclusion and participation in the community, by ensuring that persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. The Committee further recalls that persons with disabilities have the right to choose services, 14 and that while individualized support services may vary in name, type or kind according to the cultural, economic and geographic specifics of the State party, all support services must be designed to support living within the community, preventing isolation and segregation from others, and must in actuality be suitable for this purpose.15
- 9.3 In the present case, the Committee notes the author's argument that only personal assistance would be suitable for him to be able to live independently in his own home. It also notes the State party's argument that independent living can be facilitated for persons with disabilities in the form of service housing, another type of service defined in the Disability Services Act. The Committee further notes the disagreement between the parties as to the suitability of service housing for the author's needs, its availability and its acceptance by the author. In any event, the Committee notes that the State party has not demonstrated the suitability in practice of service housing for the author's needs. On the contrary, it refused his request for in-home personal assistance on the grounds that he would be unable to choose, a seemingly ableist argument that contravenes the human rights model of disability. <sup>16</sup> In the absence of elements that would reveal the practical application of this theoretical type of service, the Committee considers that the rejection of the author's application for personal

<sup>&</sup>lt;sup>11</sup> See the Committee's guidelines on the right to liberty and security of persons with disabilities (A/72/55, annex).

<sup>&</sup>lt;sup>12</sup> Y v. United Republic of Tanzania (CRPD/C/20/D/23/2014), para. 7.7.

<sup>&</sup>lt;sup>13</sup> General comment No. 5 (2017), para. 8.

<sup>&</sup>lt;sup>14</sup> Ibid., para. 28.

<sup>&</sup>lt;sup>15</sup> Ibid., para. 30.

<sup>&</sup>lt;sup>16</sup> A/HRC/43/41, paras. 9–15.

assistance has deprived him of access to a practical option that could support his living and inclusion in the community.<sup>17</sup> The Committee therefore concludes that the author's rights under article 19 (b) of the Convention have been violated.

- 9.4 The Committee notes the author's allegations of discrimination in view of the rejection by the State party's competent authorities of his application for personal assistance. It notes his argument that the resources criterion under section 8 c (2) of the Disability Services Act constitutes a barrier for persons who require support to determine the content of assistance and the modalities for providing it to enjoy personal assistance on an equal basis with others. The Committee also notes the State party's argument that the resources criterion does not make any distinction, exclusion or restriction based on disability as such, nor does it have the effect of depriving those who do not meet it of the possibility of living independently and being included in the community by other means.
- 9.5 The Committee recalls that under article 2 of the Convention, "discrimination on the basis of disability" is defined as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field, and as including all forms of discrimination, including denial of reasonable accommodation. The Committee also recalls that a law that is applied in a neutral manner may have a discriminatory effect when the particular circumstances of the individuals to whom it is applied are not taken into consideration. The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.<sup>18</sup> The Committee further recalls that indirect discrimination entails laws, policies or practices that appear neutral at face value but have a disproportionately negative impact on persons with disabilities. Indirect discrimination occurs when an opportunity that appears accessible in reality excludes certain persons owing to the fact that their status does not allow them to benefit from the opportunity itself. <sup>19</sup> The Committee observes that under article 5 (1) of the Convention, States parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law, and that under article 5 (2), States parties are required to prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- 9.6 The Committee notes that, in the present case, the author's application for a certain number of hours of personal assistance was rejected as he did not meet the resources criterion under section 8 c (2) of the Disability Services Act; that is, he does not have the ability to determine the content of the assistance he would need to live in his own house and the modalities for providing it. The Committee also notes that the author was granted a lower number of hours of personal assistance than he had requested, which were to be provided for activities outside his home, but not for those inside his home. The Committee notes the State party's argument that the purpose of personal assistance is to support the personal choices in other words, the right to self-determination of persons with disabilities. It also notes the State party's argument that that purpose cannot be fulfilled if the person with disabilities is unable to make his or her own choices. The Committee further notes the author's argument that the requirement that persons with disabilities have the ability to determine the content of assistance and the modalities for providing it without support for decision-making is discriminatory against persons with intellectual disabilities on the basis that they require support to do so.
- 9.7 In the present case, the Committee notes that the author receives personal assistance for activities outside his home. The State party has not explained the grounds on which the author was deemed to have the ability to determine his outdoor assistance, but not his indoor assistance. The State party has also not explained how such a requirement with an intellectual component the ability to determine the content of assistance and the modalities for

<sup>&</sup>lt;sup>17</sup> H.M. v. Sweden, para. 8.9.

<sup>&</sup>lt;sup>18</sup> Ibid., para. 8.3.

<sup>&</sup>lt;sup>19</sup> General comment No. 6 (2018), para. 18 (b).

providing it — makes it possible for people who require support to be able to express their choice on an equal basis with others. The Committee therefore concludes that, in the present case, in the absence of an objective and reasonable justification by the State party, the application of the resources criterion under section 8 c (2) of the Disability Services Act disproportionally affected the author, as a person who required support to meet that criterion, and resulted in him being subjected to indirect discrimination.

- 9.8 The Committee therefore finds that the relevant domestic authorities' rejection of the author's application for personal assistance on the basis of the resources criterion constituted indirect discrimination against persons with intellectual disabilities, as it had the effect of impairing or nullifying the author's enjoyment and exercise, on an equal basis with others, of the right to live independently and to be included in the community, in violation of his rights under article 5 (1) and (2), read alone and in conjunction with article 19, of the Convention.
- 9.9 In the light of the above, the Committee concludes that the State party has failed to fulfil its obligations under article 19 (b) and article 5 (1) and (2), read alone and in conjunction with article 19, of the Convention.

## C. Conclusion and recommendations

- 10. The Committee, acting under article 5 of the Optional Protocol, is of the view that the State party has failed to fulfil its obligations under article 19 (b) and article 5 (1) and (2), read alone and in conjunction with article 19, of the Convention. The Committee therefore makes the following recommendations to the State party:
  - (a) Concerning the author, the State party is under an obligation:
  - (i) To provide him with an effective remedy, including by reconsidering his application for personal assistance to ensure that he can exercise his right to live independently, in the light of the Committee's Views;
  - (ii) To provide adequate compensation to the author for the costs incurred in filing this communication;
  - (iii) To publish the present Views and circulate them widely in accessible formats so that they are available to all sectors of the population.
- (b) In general, the State party is under an obligation to take measures to prevent similar violations in the future. In that regard, the Committee requires the State party to ensure that its legislation on personal assistance and the manner in which it is applied by administrative institutions and domestic courts is consistent with the State party's obligations to ensure that legislation does not have the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise of any right by persons with intellectual disabilities on an equal basis with persons with other types of disabilities when seeking access to personal assistance;
- (c) In particular, the Committee recommends that the State party amend the Disability Services Act to ensure that the resources criterion, under which the beneficiary is required to have the ability to determine the content of the required assistance and the modalities for providing it, is not an obstacle to independent living for persons who require support in decision-making.
- 11. In accordance with article 5 of the Optional Protocol and rule 75 of the Committee's rules of procedure, the State party should submit to the Committee, within six months, a written response, including information on any action taken in the light of the present Views and the recommendations of the Committee.