

Reykjavík, 31. janúar 2018

**Efni: Umsögn málefnaþóps Öryrkjabandalags Íslands um frumvarp til laga um þjónustu við fatlað fólk með miklar stuðningsþarfir.**

Vísað er til fyrirbyggjandi umsagnar Öryrkjabandalags Íslands almennt hvað varðar einstaka þætti frumvarpsins og eru árétttaðar þær athugasemdir sem þar koma fram. Auk þess þykir ástæða til að hnykkja á eftirfarandi atriðum, sem og áréttta það sem fram kom á nefndarfundi velferðarnefndar 17. janúar síðastliðinn þar sem fulltrúar ÖBÍ, Þroskahjálpar, fötlunarfræðar Háskóla Íslands og NPA miðstöðvarinnar komu fyrir nefndina.

**1) Almennt**

- Við krefjumst þess að frumvarpið verði lögfest á þessu ári. Ef fyrirsjáanlegt er að það markmið náist ekki þá skal réttur fatlaðs fólks til NPA lögfestur með sérlögum á haustþingi. Í ljósi reynslunnar þarf að huga að þessu tímanlega en ekki í lok haustþings.
- Löggjafinn þarf að gera upp við sig hvort þau lög sem verið er að setja séu þjónustulög eða réttindalög. Sjá til dæmis 34. gr. núgildandi laga um málefni fatlaðs fólks sem hefur ekki verið fundinn staður í fyrirhuguðum frumvörpum auk þess sem ekki er vísað til mannréttindasáttmála í núverandi frumvarpsdrögum um félagsþjónustu sveitarfélaga og er því sem einstaklingum sem falla undir þau lög ekki tryggð sambærileg réttarvernd og öðrum sem falla undir lög um þjónustu við fatlað fólk með miklar stuðningsþarfir.

**2) Samráð**

Nauðsynlegt er að tryggja með lögum víðtækara samráð við fatlað fólk. Almennt er mikilvægt að í öllum samráðsnefndum sem varða fatlað fólk sé gert átak þar sem mun fleira fatlað fólk sé kallað að borðinu en verið hefur.

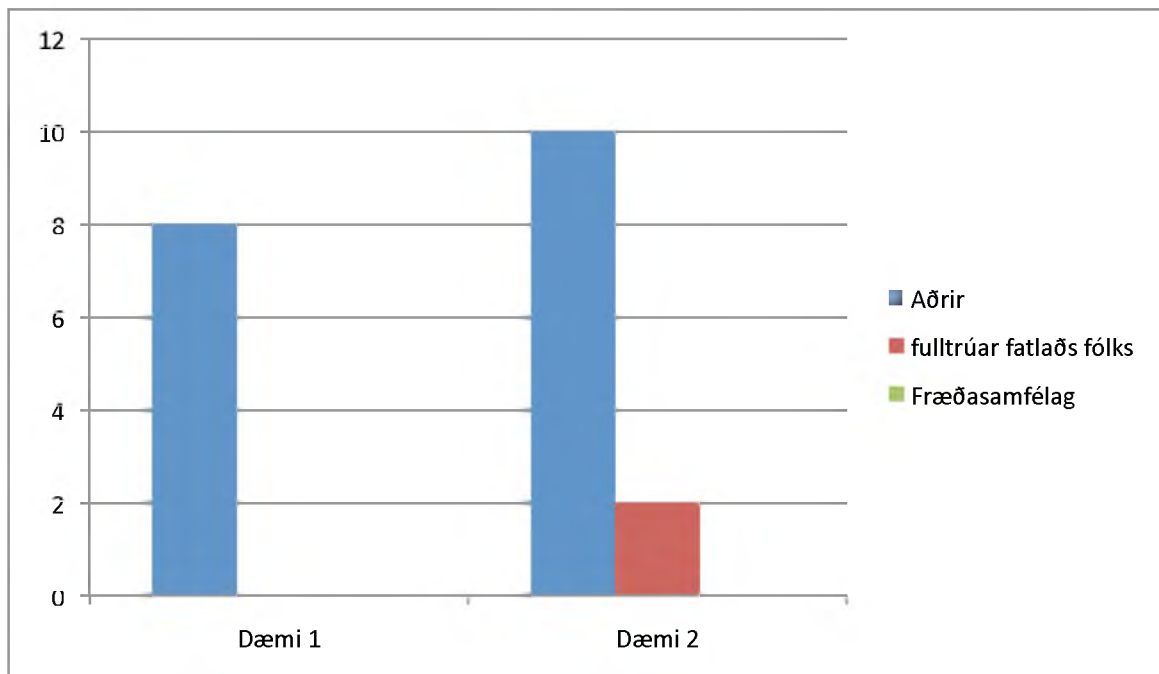
Þá er full ástæða til að skoða hvort rétt sé að greiða fyrir slík nefndarstörf, enda fylgir störfunum talsvert álag og um er að ræða lögbundna skyldu til samráðs sem leggur þar af leiðandi skyldu á fatlað fólk að taka þátt í slíku samtali. Ljóst er að greitt er fyrir ýmis

nefndarstörf í þágu þess opinbera en ekki liggur fyrir hvers vegna vinna að málefnum fatlaðra skyldi fara fram sem sjálfboðaliðastörf af hálfu fatlaðs fólks.

Neðangreint er dæmi sýnir svart á hvítu hversu bágborið samráð hefur verið við fatlað fólk í málefnum sem því tengist. Þá hafa fötlunarfræðingar lítið sem ekkert verið hafðir með í ráðum.

**Dæmi 1:** Verkefnastjórn um endurmat á yfirfærslu til sveitarfélaga (enginn fulltrúi fatlaðra)<sup>1</sup>:

**Dæmi 2:** Starfshópur um endurskoðun laga um málefni fatlaðs fólks og laga um félagsþjónustu sveitarfélaga, með vísan til ákvæðis til bráðabirgða XII í lögum um málefni fatlaðs fólks, nr. 59/1992, um að endurskoða skyldi báða lagabálkana. Starfshópurinn skyldi auk þess skyldi vinna að fullgildingu samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks í samvinnu við ráðuneytið (17. febrúar 2014.).



Vakin er sérstök athygli Alþingis á skyldu til samráðs skv. Samningi Sameinuðu þjóðanna um réttindi fatlaðs fólks (SRFF), sjá grein 4(3):

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, **States Parties shall closely consult with and actively involve persons with disabilities**, including children with disabilities, through their representative organizations.

<sup>1</sup> Sjá: [https://www.stjornarradid.is/media/velferdarraduneyti-media/media/rit-og-skyrslur-2015/Endurmat\\_a\\_yfirfaerslu\\_malefna\\_fatlads\\_folks\\_11122015.pdf](https://www.stjornarradid.is/media/velferdarraduneyti-media/media/rit-og-skyrslur-2015/Endurmat_a_yfirfaerslu_malefna_fatlads_folks_11122015.pdf)

**Tillaga:** Lagt er til að tryggja sé með orðalagi 36. gr. frumvarpsins að í samráðsnefnd um málefni fatlaðs fólks sitji ekki færri fulltrúar fatlaðra en aðrir og að fulltrúar nefndarinnar tengist málefnum fatlaðra með eðlilegum hætti<sup>2</sup>.

### 3) Mismunun:

- a) **Skerðingar:** Heiti lagafrumvarps endurspeglar innbyggða mismunun gagnvart ólíkum hópum fatlaðra sem felur í sér augljóst brot á SRFF. Mikilvægt að hér sé áréttað að óheimilt sé að mismuna fólki eftir fötlun.

**Tillaga A:** Skipta út orðinu „miklar“ fyrir orðið „langvarandi“ í heiti lagafrumvarpsins.

**Tillaga B:** Ef það er ætlun löggjafans að halda áfram að aðgreina á milli stigs þjónustubarfa verður nauðsynlega að skilgreina hvað „miklar“ þjónustubarfir er í sjálfum lagatextanum. Nú gætir mikils ósamræmis og ruglings um hvar þau mörk liggja. Auk þess er óskýrt í lagatexta fyrirbyggjandi frumvarps hver munur sé á hugtökunum „þjónustubörf“ og „stuðningsbörf“ og hvernig beri að meta slíkar þarfir. Mikilvægt er að sjálfsmat notanda sé lagt til grundvallar.

**Tillaga C:** Til að tryggja mannréttindavernd skv. SRFF þeirra sem falla undir lög um félagsþjónustu, líkt og gert er í sérlegafrumvarpinu, verður að bæta inn sambærilegri grein um mannréttindavernd fatlaðra í félagsþjónustulögin. Auk þess þarf að vísa í NPA hugmyndafræði varðandi notendasamninga í félagsþjónustulögunum.

- b) **Aldur.** Útilokun barna eins og ýjað er að í greinargerð frumvarpsins stenst hvorki SRFF né Barnasáttmála Sameinuðu þjóðanna, sjá sameiginlega bókun sem hefur verið send velferðarnefnd, dags. 28. nóvember 2017 sem að stóðu: ÖBÍ, Þroskahjálp, NPA-miðstöðin, Landssamtökin Þroskahjálp, Tabú – feminísk fötlunarhreyfing, Átak – félag fólks með þroskahömlun og Rannsóknasetur í fötlunarfræðum. Að þeim hluta bókunarinnar sem snéri að rétti fatlaðra barna stóðu einnig: Umboðsmaður barna, UNICEF og Barnaheill sem mótmæla öll sem eitt slíkri mismunun á grundvelli aldurs.
- c) **Tillaga A (úr umsögn NPA miðstöðvar á fyrri stigum):** „Þó er óljóst hvað átt er við með því að aðstoðin skuli „skipulögð á forsendum notandans undir verkstýringu og verkstjórn hans“ og hvort það hafi áhrif á rétt ungmenna til þess að vera með NPA. Í frumvarpinu virðist vera gert ráð fyrir að ungmenni eigi rétt á NPA sem er fagnaðarefni en í athugasemdum við III. kafla laganna kemur fram að ákvæði kaflans eigi að meginsteftu við um þjónustu við fullorðna. Að mati NPA miðstöðvarinnar er mikilvægt að skýra betur rétt ungmenna til NPA, sérstaklega þegar 10. og 11. gr. frumvarpsins eru skoðaðar saman. Þannig segir í 3. mgr. 10. gr. um

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<sup>2</sup> Erfitt er t.d. að henda reiður á hvers vegna fulltrúar frá Hjálparstofnun kirkjunnar og Rauða krossi Íslands hafi verið kallaðir að samráði frekar en að auka hlut fatlaðs fólks og hagsmunasamtaka þeirra í slíku samtali.

notendasamninga, en undir það falla NPA samningar, að „einstaklingar og barnafjölskyldur“ geti sótt um að gera notendasamning. Ekki er ljóst hvað átt er við með því að tilgreina barnafjölskyldur þarna sérstaklega eða hvaða tilgangi það þjónar. Gera má ráð fyrir að þarna sé átt við foreldra fatlaðra barna en æskilegt væri að skýra það nánar. NPA miðstöðin leggur einnig til að ungmennum verði gert kleift að hafa NPA ásamt aðstoð við verkstjórn með því að breyta 2. mgr. 10. gr. frumvarpsins á þann veg að í stað orðanna „Ef notandinn á erfitt með að annast verkstjórn vegna fötlunar sinnar...“ komi „ Ef notandinn á erfitt með að annast verkstjórn vegna fötlunar sinnar eða aldurs...“.

#### 4) Búseta

Nú þegar er mikið misræmi milli réttar til NPA eftir þjónustusvæðum. Auk þess er fötluðu fólki mismunað innan sveitarfélaga.

Um þjónustusvæði vísuð við til sameiginlegs minnisblaðs fyrrgreinds samráðshóps sem kom fyrir velferðarnefnd í janúar 2018, sjá fylgiskjal b.

Tryggja þarf jöfnuð fatlaðs fólks á landsvísu og að hægt sé að flytja auðveldlega milli landssvæða. Hvað þetta varðar má líta til tilraunaverkefnis í Noregi þar sem leitast er við að færa NPA þjónustu á hendur ríkis fremur en sveitarfélaga. Um er að ræða 3ja ára verkefni þar sem ríkið fjármagnar alfarið NPA og fleiri þjónustur í 18 sveitarfélögum, en tilraunaverkefnið hófst 1. maí 2016.

Virðingarfyllst,

**Þuríður Harpa Sigurðardóttir**, formaður ÖBÍ

**Rúnar Björn Hererra Þorkelsson**, formaður málefnaþóps ÖBÍ um sjálfstætt líf

#### Fylgiskjöl

- a) Minnisblað um SIS mat, dags. 15. janúar 2018.
- b) Minnisblað þjónustusvæði, dags. 17. janúar 2018.
- c) Almennar ábendingar nr. 5 frá eftirlitsnefnd Sameinuðu þjóðanna um réttindi fatlaðs fólks, dags. 14-31. ágúst 2017.

## MINNISBLAÐ UM SIS-MAT

**Frá: Samstarfshópi um ný frumvörp, reglugerðir og NPA handbók**

**Efni: SIS-mat og framkvæmd þess í USA, Kanada og Íslandi**

**Dagsetning: 15. janúar 2018**

**Um samstarfshópinn:** Í hópnum eru fulltrúar frá NPA miðstöðinni, Landssamtökunum Þroskahjálp, Rannsóknasetri í fötlunarfræðum við Háskóla Íslands, Tabú og Öryrkjabandalagi Íslands.

Minnisblað þetta dregur fram helstu gagnrýni samstarfshópsins á SIS-matið og framkvæmd þess á Íslandi. Við gerum alvarlegar athugasemdir við SIS-matið almennt og hvernig það er framkvæmd hér á landi. Einkum mótmælum við því að SIS-mat verði skilyrði fyrir því að einstaklingur geti sótt um NPA eins og nú er kveðið á um í II. KAFLA, 5. grein draga að Reglugerð um NPA, en þar segir:

Einstaklingur sem fellur undir gildissvið 1. gr. getur sótt um NPA til þess sveitarfélags þar sem hann á lögheimili. Skilyrði fyrir því að einstaklingur geti sótt um NPA er að fyrir liggja almennt félagsþjónustumat (grunumat) og SIS-mat eða annað sambærilegt mat.

Við gerum mjög alvarlegar athugasemdir við þessar fyrirætlanir. Gagnrýni okkar á SIS-matið og framkvæmd þess byggir á íslenskum rannsóknum og úttektum, og erlendum greinum og skýrslum. Helstu heimildir er að finna aftast í minnisblaði þessu. Allar heimildir sem við vitnum til, nema ein, eru „óháðar“. Það er, þessar heimildir eru ekki skrifaðar af höfundum SIS-matsins eða þeim aðilum sem eiga hagsmuna að gæta, svo sem þeim sem hafa innleitt matið, staðfært og standa að framkvæmd þess.

### I. Gagnrýni á matið SIS-matið sjálft.

**1. Matið er mjög dýrt í staðfæringu, innleiðingu og framkvæmd.** Að áliti sérfræðinga er SIS eitt dýrasta matstækið sem nú er á „markaðnum.“ Sérfræðingar benda á að það sé sérlega dýrt í notkun ef því er ætlað að greina eða meta alla einstaklinga sem eru með eina eða fleiri skerðingar.

**2. SIS matið flokkar fatlað fólk og smættar það niður í eina tölu á bilinu 1 – 7** eftir því í hvaða stuðningsflokk viðkomandi lendir skv. matinu. Margir fatlaðir einstaklingar (og aðstandendur þeirra) **benda á að matið sé ómannúðlegt og niðurlægjandi.** Sumir bera SIS-matið saman við hvernig fólk með þroskahömlun (sem matið er hannað fyrir) var flokkað hér áður fyrr eftir einni tölu (greindarvísitölu) og í framhaldi af því flokkað sem „idiot“, „imbecil“ o.s.frv. Í USA, þaðan sem SIS matið er ættað, og í Kanada, er að finna alvarlega gagnrýni á þetta atriði, ekki síður en hér á landi. Í Alberta ríki í Kanada var hætt að nota SIS-matið vegna gagnrýni af þessum toga frá fötluðu fólki, fjölskyldum þeirra og fagfólki.

**3. SIS-matið leitar eftir miklu af viðkvæmum persónulegum upplýsingum,** sem hafa lítið með mat á stuðningsþörf að gera. Þátttakendur í matinu á Íslandi telja sumir að **matið gangi nærri friðhelgi einkalífs.**

**4. SIS-matið er staðlaður spurningalisti. Allir eru spurðir sömu spurninga.** Þ.e. SIS-matið er ekki einstaklingsbundið og það tekur ekki tillit til persónulegra óska og vilja, eða sérþarfa hvers og eins (sem er lykilatriði í NPA þjónustu) heldur er staðlað og notast við sömu spurningar fyrir alla. Þessi gagnrýni kemur fram í bæði íslenskum rannsóknum og greinum, og erlendum heimildum.

**5. SIS-matið virðist gera ráð fyrir að fagfólk og þjónustuveitendur eigi síðasta orðið í skilgreiningu á þörfum fólks og völd til að skilgreina hvað skuli taka við að mati loknu.** Þetta er ein afleiðing þess að matið er staðalað og ópersónulegt og því taka niðurstöður ekki mið af persónulegum óskum og vilja fólks.

## Samantekið um SIS-matið sjálft

### Sérstaklega hvað varðar mat á NPA umsóknum

(Á líka við um mat á stuðningsþörfum fatlaðs fólks almennt)

Ef markmiðið er að veita einstaklingsbundna og sveigjanlega þjónustu þá gengur ekki að kerfið sé drifið áfram af einfölduðum flokkunum smættuðum niður í eitt númer. Matið verður að vera einstaklingsbundið og persónulegt. Annað er í mótsögn við hugmyndafræðina um NPA, ákvæði Samnings SP um réttindi fatlaðs fólks og markið þeirra frumvarpa sem nú liggja fyrir Alþingi.

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## II. Gagnrýni á framkvæmd SIS-matsins

**1. Við gerum alvarlegar athugasemdir við að SIS-matið er ekki notað hér á landi á þann hátt sem höfundar þess ætla því að vera notað** (sbr. skýrslu Kristínar S. Sigursveisdóttur, 2012 bls. 18-19), en þar segir:

SIS var fyrst og fremst þróað með það í huga að vera verkfæri við gerð einstaklingsbundinna þjónustuáætlaða en höfundar bentu einnig á þann möguleika að nota niðurstöður við skipulag þjónustu fyrir stærri hópa eða svæði, við ákvörðun fjárveitinga og við skiptingu fjárveitinga t.d. milli þjónustuveitenda. Höfundar gjalda varhug við því að nota eingöngu niðurstöður SIS-mats, líta beri á það sem einn „bita í púslið“ (Thompson o.fl., 2004).

**Hér á landi er SIS-matið einvörðungu notað til að deila út fjármunum.** Eins og fram kemur í erlendum og íslenskum heimildum er það talið sérlega gagnrýnivert hvernig SIS er notað sem tæki til að deila út fjármunum á grundvelli einnar tölu og þvert á það sem höfundar matsins ætla því.

**2. SIS-matið er hannað fyrir fólk með þroskahömlun.** Hér á landi er matið hins vegar notað fyrir allt fatlað fólk óháð skerðingu. Við gagnrýnum harðlega þessa framkvæmd. Í íslenskum rannsóknum kemur fram að matið á mismunandi vel við ólíkar skerðingar og

metur illa og af mikilli ónámvæmni stuðningsþarfir fólks með hreyfihömlun, geðfötlun og hegðunarvanda.<sup>1</sup>

**3. Í erlendri gagnrýni á framkvæmd SIS matsins kemur í ljós að það hefur iðulega verið notað til að hindra aðgang að þjónustu og réttlæta skerðingu fjárveitinga – stundum með afar einföldum hætti því niðurskurðurinn beinist að stuðnings-flokkum sem byggjast á einni tölu, óháð einstaklingsbundnum þörfum fólksins.**

**4. Í framkvæmd á Íslandi er SIS-matið hvorki notað til að bæta stuðning og þjónustu fólks sem matið er, né til að vinna einstaklingsbundnar þjónustu- eða stuðningsáætlanir.** Þetta kemur fram íslenskum heimildum. Í MA ritgerð Bjargeyjar Unu Hiniksdóttur (2016 bls. 60) segir um þátttakendur í SIS-matinu:

Langflestir tóku þátt í matinu í þeirri trú að upplýsingarnar, sem margar voru mjög persónulegar, yrðu nýttar til að bæta aðstoð þeirra en raunin var svo önnur – þar sem aldrei stóð til að nýta þær í þeirra þágu heldur í þágu sveitarfélagana til að úthluta fjármagni til þjónustuaðila. Má því segja að viðmælendur hafi tekið þátt í SIS – matinu á röngum forsendum. Þetta er umhugsunarvert í ljósi þess að flestir töldu að þeir fengju meiri aðstoð en þeir fá í dag ef niðurstöður SIS – matsins væru nýttar til að áætla stuðningsþörf þeirra.

Viðtalið sem SIS- matið byggir á er langt og flókið þar sem m.a. er beðið um nánar og viðkvæmar persónulega upplýsingar. Ef matið er ekki notað til að bæta stuðning og þjónustu vekur það áleitnar spurningar um hvort það er réttlætanlegt að nota þetta dýra og flókna mat til þess eins að útdeila fjármagni byggt á einni tölu.

**5. Erlendar úttektir hafa sýnt að SIS-matið er oft óáreiðanlegt í framkvæmd og metur stuðningsþarfir ekki rétt. Það sé því sums staðar talið óviðunandi sem grundvöllur fjárveitinga.** Þetta kemur m.a. fram í óháðri úttekt á framkvæmd SIS-matsins í Virginíu ríki í USA (sjá heimild aftast).

Í niðurstöðukafla úttektarinnar kemur fram að framkvæmd SIS-matsins er flókin og jafnframt talsvert mismunandi á milli þeirra 15 ríka í USA sem notuðu það þegar úttektin fór fram árið 2013. Bent er á að þegar SIS er notað til að útdeila fjármunum skiptir mestu að niðurstöður matsins (viðtalsins) séu lausar við hagsmunaárekstra, nákvæmar og áreiðanlegar. Þetta felur í sér að þeir sem fá þjálfun til að framkvæma viðtalið/matið hafi ekki hagsmuna að gæta varðandi niðurstöðurnar, séu þjálfaðir á viðurkenndan hátt, viðurkenndir sem SIS spylrar, lúti reglubundnu eftirliti með frammistöðu sinni og fái leiðbeiningar og séu leiðréttir eftir þörfum.

Í stuttu máli er niðurstaða úttektarinnar á framkvæmd SIS-matsins í Virginíuríki sú að mikið vantaði upp á að framkvæmdin sé í lagi og raktir margir þættir þar að lútandi, m.a. þjálfun spyrlla, eftirlit með framkvæmd (matsviðtalinu) og niðurstöðum, mat á áreiðanleika niðurstaðna, samræmi milli matsviðtala, og fleira. Í skýrslunni eru settar fram margar ábendingar um breytta framkvæmd matsins. Meðal annars er fyrsta tillagan sú að framkvæmdin væri svo óáreiðanleg að tafarlaust ætti að hætta að nota SIS- matið með þeim hætti sem gert er og alls ekki nota það mat sem þegar hafði verið unnið sem

**grundvöll fjárveitinga. Eins og matið væri framkvæmt væri það óviðunandi sem grundvöllur á útteilingu fjár.**

**Engin óháð úttekt hefur verið gerð á því hvernig SIS-matið er framkvæmt hér á landi.** Afar mikilvægt er að slík óháð úttekt verði gerð til að unnt sé að leggja mat á það hvort það er ásættanlegt hvernig staðið er að framkvæmdinni hér á landi.

**6. Eins og yfirvöld víða um heim vilja íslensk yfirvöld nota SIS til að deila út fjármunum á réttlátari hátt** en gert var fyrir daga SIS matsins, þegar fólk með svipaðar stuðningaþarfir fékk mismunandi fjárveitingu/þjónustu. Við bendum á að það sama gerist með fjárveitingum byggðar á SIS mati og fyrri matstækjum. SIS-matið tryggir alls ekki að fjármunum sé deilt á réttlátan hátt. Þrátt fyrir að einstaklingar séu með sömu eða svipaða skerðingu og þar með metnir með svipaðar stuðningsþarfir þá geta viðkomandi búið við ólíkar aðstæður, haft mismunandi áhugamál, þarfir, óskir og lífsstíl. Ef litið er til óska og þarfa fatlaðs fólks er ljóst að stöðluð og ópersónuleg útteiling fjár, byggð á einni tölu, er ekki í samræmi við nútíma hugmyndafræði um einstaklingsbundna þjónustu.

**7. Rannsóknir á framkvæmd SIS-matsins hér á landi sýnir að það er löng bið eftir því að fá mat. Auk þess er löng bið eftir niðurstöðum matsins.** Matið er því í sumum tilvikum úrelt þegar það er sent til þjónustuaðilans.

**8. Við gagnrýnum jafnframt að niðurstöður matsins eru sjaldan eða ekki kynntar fyrir þeim sem fara í SIS-mat.** Í MA ritgerð Bjarneyjar Unu Hiniksdóttur (2016 bls. 60) segir um þátttakendur í rannsókn hennar sem höfðu farið í SIS-mat: „Athyglisvert er að þátttakendur fengu hvorki kynningu á niðurstöðum eða tækifæri til samtals um hvernig þeir vildu að þörf þeirra væri mætt.“ Sama gagnrýni kom fram varðandi skort á kynningu á matinu áður en fólk fór í matið.

## **Samantekið um framkvæmd SIS-matsins**

### **Sérstaklega hvað varðar mat á NPA umsóknum**

Óháðar úttektir svo og fatlað fólk, fjölskyldur þeirra og fagfólk, hér á landi og erlendis, hafa sett fram mjög alvarlega gagnrýni á framkvæmd SIS-matsins. Bent er á að það sé óviðunandi að matstæki sem ætlað er sem grundvöllur fjárveitinga og þjónustu skuli vera jafn umdeilt og raun ber vitni. Og skuli þar að auki vera mjög kostnaðarsamt og svo flókið í framkvæmd að erfitt er að framkvæma matið þannig að ásættanlegt er.

Mikilvægt er að notkun SIS-matsins sé endurskoðuð, bæði matið sjálft en ekki síður hvernig það er framkvæmt hér á landi. Gera þarf óháða úttekt á matinu, kostnaði við það, árangri þess og reynslu helstu hagamunaaðila.

**Þar til slík úttekt hefur farið fram leggjumst við eindregið gegn því að það sé innleitt sem mat á umsóknum um NPA þjónustu.**

Það er fjöldi matstækja sem mætti nota í staðinn fyrir SIS-matið en við teljum mikilvægt að áherslan verði ekki einungis á að finna eitthvað í stað SIS sem getur metið þarfir fólks. Á sama tíma og við teljum að innleiða ætti matstæki sem m þjónar þörfum fatlaðs fólks betur



en SIS-matið, en leggjum ekki síður áherslu á að endurskilgreina hvað á að vera í forgangi. Að okkar mati á ekki að beina fjármagni og orku í það að leggja ofuráhersla á mat á þjónustupörfum. Það er ekki það sem skiptir mestu.

Í stað þess að ausa fé í mat á stuðningspörfum leggjum við áherslu á féð verði notið í aukna og bættu þjónustu og að þróað sé fyrirkomulag sem er sniðið að einstaklingsbundnum þörfum fatlaðs fólks og stuðlar að jafnrétti, mannréttindum og samfélagsþátttöku.

## Samrýmist ekki Samningi Sameinuðu þjóðanna um Réttindi fatlaðs fólks

Að lokum er vakin athygli á því að Nefnd Sameinuðu þjóðanna um réttindi fatlaðs fólks gaf nýlega út almennar ábendingar nr. 5 um hvernig túlka skuli 19. gr. Samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks (SRFF). Greinin fjallar um rétt fatlaðs fólks til að lifa sjálfstæðu lífi og vera þátttakendur í samfélaginu. Hvað varðar greiningaraðferðir segir m.a. í þessum athugasemdum um hvernig greinin skuli túlkuð eftirfarandi:

**61. States parties shall incorporate the following elements into the eligibility criteria for access assistance:** The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment, take into account, and follow a person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process.

**63. Support** for persons with disabilities should be assessed, through a personalised approach, and tailored to the specific activities and actual barriers that persons with disabilities face in being included in the community. The assessment should acknowledge that persons with disabilities require access to participate in activities that are varying over time. States parties should ensure that personalization of support, including cash transfers/personal budgets, take into account and address the challenges that persons with disabilities face when living in rural and/or urban areas.

Af þessum leiðbeiningum um hvernig túlka beri samninginn er ljóst að sú aðferð að beita SIS mati alhliða á alla einstaklinga sem sækja um NPA er óhæf og samrýmist ekki SSPFF.

## Helstu heimildir (ef óskað er eftir getum við vísað í fleiri heimildir)

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## Heimild frá höfundum SIS-matsins

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<sup>1</sup> Ath. íslenskar rannsóknir sem hafa fjalla um notkun á SIS-mati með öðrum hópum en fólki með þroskahömlum hafa metið fólk með þroskahömlun og aðrar skerðingar s.s. geðræn vandamál eða hreyfihömlun.



HÁSKÓLI ÍSLANDS  
RANNSÓKNASETUR Í FÖTLUNARFRÆÐUM

**Minnisblað varðandi þjónustusvæði með lágmarksfjölda íbúa.**

**Frá: Samstarfshópi um ný frumvörp, reglugerðir og NPA handbók**

**Efni: Skipting landsins í þjónustusvæði og skilyrðið um 8000 íbúa þjónustusvæði fellt úr gildi**

**Dagsetning: 17. janúar 2018**

**Um samstarfshópin:** Í hópnum eru fulltrúar frá NPA miðstöðinni, Landsamtökunum Þroskahjálpi, Rannsóknasetri í fötlunarfræðum við Háskóla Íslands, Tabú og Öryrkjabandalagi Íslands.

Í fyrirbyggjandi frumvarpi til laga um þjónustu við fatlað fólk með miklar stuðningsþarfir er gert ráð fyrir að horfið verði frá núgildandi ákvæðum varðandi skiptingu landsins í þjónustusvæði við fatlað fólk og að hverju og einu sveitarfélagi verði heimilað að annast þessa þjónustu. Í athugasemdum í frumvarpinu segir um þetta:

*Í 6. mgr. er kveðið á um að sveitarfélagi sé unnt að fela öðru sveitarfélagi eða lögaðila að taka ákvarðanir um þjónustu samkvæmt lögum, en það er breyting frá því sem nú er kveðið á um í lögum um málefni fatlaðs fólks. Í 2. mgr. 4. gr. þeirra laga segir að landinu skuli skipt í þjónustusvæði þar sem séu að lágmarki 8.000 íbúar. Þannig er fallið frá því að um skyldu sé að ræða, verði frumvarp þetta að lögum, og sveitarfélögum gert þetta heimilt.*

Vegna þessa er óhjákvæmilegt að benda á að sveitarfélög í landinu eru nú um 70 talsins, mjög misjafnlega fjölmenn og þar af leiðandi mjög misjafnlega í stakk búin til að veita fötluðu fólki þá margbreytilegu þjónustu sem það á rétt á lögum samkvæmt og hefur afar mikla hagsmuni af því að fá. Það er því nauðsynlegt að rifja upp á hvaða rökum og sjónarmiðum sú ákvörðun löggjafans byggðist að samþykkja ákvæði um þjónustusvæði þegar ábyrgð á þjónustu við fatlað fólk var færð frá ríki til sveitarfélaga árið 2011.

Þau ákvæði er að finna í 4. gr. laga nr. 59/1992, um málefni fatlaðs fólks og hljóða þau svo:

*Landinu skal skipt í þjónustusvæði þannig að á hverju þjónustusvæði séu að lágmarki 8.000 íbúar. Fámennari sveitarfélög skulu hafa samvinnu við önnur sveitarfélög um skipulag og framkvæmd þjónustu við fatlað fólk skv. 1. mgr. og bera þau þá sameiginlega ábyrgð á skipulagi og framkvæmd þjónustunnar sem og kostnaði vegna hennar nema annað sé tekið fram eða leiði af öðrum lögum.*

...

*Ráðherra er heimilt að veita undanþágu frá íbúafjölda skv. 2. mgr. á grundvelli landfræðilegra aðstæðna, enda hafi viðkomandi sveitarfélag eða sveitarfélög sýnt fram á getu til að veita þjónustu í samræmi við ákvæði laga þessara.*

Náist ekki samkomulag milli sveitarfélaga um að mynda þjónustusvæði skv. 2. mgr. getur ráðherra, að höfðu samráði við Samband íslenskra sveitarfélaga, tekið ákvarðanir um stærð eða mörk þjónustusvæða og eru þær ákvarðanir bindandi fyrir hlutaðeigandi sveitarfélög.

Um tilgang þessara ákvæða um þjónustusvæði með lágmarksfjölda íbúa segir í athugasemdum í lagafrumvarpinu þar sem mælt var fyrir um þjónustusvæðin:

Lagt er til að landinu verði skipt í þjónustusvæði þannig að á hverju þjónustusvæði séu að lágmarki 8.000 íbúar. Er því gert ráð fyrir að sveitarfélög með færri en 8.000 íbúa hafi samvinnu við önnur sveitarfélög um skipulag og framkvæmd þjónustu við fatlað fólk þar sem ekki var talið rekstrarlega hagkvæmt fyrir fámennari sveitarfélög að standa ein að þjónustunni þannig að gæði væru nægilega tryggð. Tilgangur þjónustusvæða er því að tryggja að þeir sem veita þjónustuna hafi faðlega og fjárhagslega getu til að sinna verkefninu. Enn fremur standa vonir til að einstök þjónustusvæði geti stuðlað að almennri eflingu félagsþjónustu sveitarfélaga en mikilvægt er að þjónustusvæðin hafi yfir að ráða fjölbreyttum þjónustuúrræðum og nauðsynlegri sérþekkingu í málaflokknum til þess að geta sinnt verkefninu. Faðlegur viðbúnaður þarf að vera til staðar svo að unnt sé að mæta þeim þjónustubörfum sem fyrir hendi eru með tiltölulega skömmum fyrirvara, svo sem vegna fæðingar fatlaðs barns eða flutnings fatlaðs einstaklings á svæðið. Enn fremur er með þessu skipulagi leitast við að takmarka áhættu af sveiflum í fjölda og þjónustubörfum fatlaðs fólks.

...

Ljóst er að í ákveðnum tilvikum er það erfiðleikum bundið að mynda þjónustusvæði með 8.000 eða fleiri íbúa í samræmi við 2. mgr. ákvæðis þessa í ljósi landfræðilegra aðstæðna. Í því sambandi má nefna níu sveitarfélög innan Fjórðungssambands Vestfirðinga, Sveitarfélagið Hornafjörð, Norðurþing og Vestmannaeyjabæ. Því er gert ráð fyrir að ráðherra velferðarmála sé heimilt að veita undanþágu frá skilyrðinu um íbúafjölda á þjónustusvæði á grundvelli landfræðilegra aðstæðna enda hafi viðkomandi sveitarfélag eða sveitarfélög sýnt fram á getu til að veita þjónustu í samræmi við ákvæði laganna. Þá er gert ráð fyrir að til þess geti komið að sveitarfélög nái ekki samkomulagi sín á milli um myndun þjónustusvæðis og er lagt til að velferðarráðherra sé þá heimilt, að höfðu samráði við Samband íslenskra sveitarfélaga, að taka ákvarðanir um stærð eða mörk þjónustusvæða. Þær ákvarðanir yrðu bindandi fyrir hlutaðeigandi sveitarfélög.

Ekki verður annað séð en þessi rök fyrir þjónustusvæðum með lágmarksfjölda íbúa séu enn í fullu gildi. Og raunar er það svo að í þeim frumvörpum sem nú liggja fyrir, þ.e. um þjónustu við fatlað fólk með miklar stuðningsþarfar og um breytingu á lögum um félagsþjónustu sveitarfélaga, eru mikilvæg nýmæli sem styrkja þessi rök fyrir þjónustusvæðunum enn frekar. Þar má nefna ákvæði um skyldur til að hafa **starfsfólk með tiltekna fagmenntun** og ákvæði um **notendaráð og notendasamráð**. Augljóst er að til að geta uppfyllt þessi skilyrði svo vel sé er afar æskilegt að þjónustusvæðin séu ekki of fámenn.

Þá verður að benda á að sú aðferð sem nú er höfð til að skipta fé milli þjónustusvæða kann að eiga illa við ef umrædd breyting verður gerð á lögnum og sýnist því nauðsynlegt að skoða það áður en slík ákvörðun verður tekin.

Og síðast en ekki síst. Ef að umrædd breyting á lögum varðandi þjónustusvæði nær fram að ganga verður enn örðugra en nú er fyrir ríkið að standa við þá **lagalegu skyldu sína að tryggja jafnræði og samræmi milli búsetusvæða** fatlaðs fólks. Það er nú þegar brýnt og snúið viðfangsefni og verður enn örðugra viðfangs með fleiri „þjónustueiningum“. Í því sambandi verður að líta til þess að það er alvarlegt brot gegn mannréttindum ef íbúum landsins er mismunað á grundvelli búsetu hvað varðar

þjónustu þar sem í húfi eru mjög miklir hagsmunir og réttindi þeirra sem í hlut eiga og mjög oft er þjónustan forsenda þess að þeir sem á henni þurfa að halda fái notið mikilsverðra mannréttinda í skilningi laga.

Einnig verður í þessu sambandi að líta til þess að ósamræmi og/eða ójafnræði á milli búsetusvæða að þessu leyti vegur einnig mjög alvarlega að tækifærum fatlaðs fólks til að flytjast á milli svæða og mest að tækifærum þeirra sem hafa miklar þjónustufarir vegna fötlunar sinnar og eru því mest háðir þjónustunni. Rétturinn til að ráða búsetu sinni er mannréttindi í skilningi stjórnarskrár og mannréttindasamninga. Eftir því sem „þjónustueiningarnar“ verða fleiri eykst hætta á ósamræmi milli þeirra eðli máls samkvæmt.

**Með vísan til þess sem að framan er rakið verður að vara mjög við þeirri breytingu varðandi þjónustusvæði sem gert er ráð fyrir í fyrir liggjandi frumvarpi og er skorað á velferðarnefnd og Alþingi að taka þau ákvæði frumvarpsins til endurskoðunar.**



# Convention on the Rights of Persons with Disabilities

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## Committee on the Rights of Persons with Disabilities

**Eighteenth session**

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Item 8 of the provisional agenda

**General comments**

### **General comment on article 19: Living independently and being included in the community**

#### **I. Introduction**

1. Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is unavailable or tied to particular living arrangements and community infrastructure is not universally designed. Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation.

2. Article 19 of the Convention on the Rights of Persons with Disabilities recognises the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives. The foundation is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth.

3. Article 19 emphasizes that persons with disabilities are subjects of rights and rights-holders. The general principles of the Convention (art. 3), particularly respect for the individual's inherent dignity, autonomy and independence (art. 3 (a)), and the full and effective participation and inclusion in society (art. 3 (c)), are the foundation of the right to live independently and be included in the community. Other principles enshrined in the Convention are also essential to interpret and apply article 19.

4. Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities are in line with universal design prerogatives.

5. In the Preamble to the Convention, States parties recognized that many persons with disabilities live in poverty and stressed the need to address the impact of poverty. The cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation, abuse in addition to negative stereotypes that feed into a cycle of marginalization against persons with disabilities. Policies and concrete plans of action for social inclusion of persons with disabilities, including through the promotion of their right to independent living (article 19), represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.

6. The present General Comment aims at assisting States parties in their implementation of article 19 and fulfilling their obligations under the Convention. It primarily concerns the obligations to ensure every individual's enjoyment of the right to live independently and be included in the community, but it is also related to other provisions. Article 19 plays a distinct role as one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral for the implementation of the Convention across all articles.

7. Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights enshrined in this norm are fulfilled. International human rights law imposes obligations which are of immediate effect and others which may be realized progressively<sup>1</sup>. Full realization also requires structural changes that may need to be taken in stages, no matter whether civil and political or social, economic and cultural rights are at stake.

8. Article 19 reflects the diversity of cultural approaches to human living and ensures that its content is not biased towards certain cultural norms and values. Living independently and being included in the community are concepts of human living across the globe, applied to the context of disability. They mean exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society. The realization of the right must be effective in different economic, social, cultural and political contexts. The right to live independently and be included in the community refers to all persons with disabilities, irrespective of race, colour, descent, sex, pregnancy and maternity, civil, family or carer situation, gender identity, sexual orientation, language, religion, political or other opinion, national, ethnic, indigenous or social origin, migrant, asylum seeking or refugee status, association with a national minority member, economic status or property, health status, genetic or other predisposition towards illness birth, and age, or any other status.

9. The right in article 19 is deeply rooted within the international human rights law. The Universal Declaration of Human Rights stresses in article 29 (1) the interdependence of an individual's personal development and the social aspect of being a part of the community: "Everyone has duties to the community in which alone the free and full development of his personality is possible". Article 19 has its roots in civil and political as well as economic, social and cultural rights: The right to liberty of movement and freedom to choose one's residence (art. 12 of the International Covenant on Civil and Political Rights) and the right to an adequate standard of living, including adequate clothing, food and housing (art. 11 of the International Covenant on Economic, Social and Cultural Rights) and to basic communication rights form the basis for the right to live independently and be included in the community. Liberty of movement, an adequate standard of living as well as the ability to understand and have one's preferences, choices and decisions understood, form indispensable conditions for human dignity and the free development of a person.<sup>2</sup>

10. The Convention on the Elimination of All Forms of Discrimination against Women emphasizes the equality of women and men and condemns discrimination against women in all its forms (art.1). The Convention reaffirms the equality between women and men concerning legal matters, including legal capacity and opportunities to exercise that capacity (art. 15 (2)). It also requests States parties to recognize the same rights with regard

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<sup>1</sup> Committee on Economic, Social and Cultural Rights (CESCR), General comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant), 14 December 1990, E/1991/23, paras. 1-2.

<sup>2</sup> The Universal Declaration of Human Rights article 22; Human Rights Committee, General comment No. 27, para. 1; Committee on Economic, Social and Cultural Rights, General comment No. 4, para. 7.

to the law relating to the movement of persons and the freedom to choose their residence and domicile (art. 15 (4)).

11. Article 9 (1) of the Convention on the Rights of the Child requires State parties to “ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interest of the child”. States parties to this Convention “shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities” as guaranteed by article 18 (2). In addition, article 20 establishes that “a child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State” (Art. 20 (1)), and “States parties shall in accordance with their national laws ensure alternative care for such a child” (Art. 20 (2)). Alternative care provided on the grounds of disability would be discriminatory.

12. Article 23 (1) further establishes that all children with disabilities should to enjoy a life in dignity in conditions which ensure self-reliance and facilitate active participation in the community. The Committee on the Rights of the Child has expressed its concern at the high number of children with disabilities placed in institutions and urged States parties through de-institutionalization programs supporting their ability to live in their family, extended family or foster care.<sup>3</sup>

13. Equality and non-discrimination are fundamental principles of international human rights law and enshrined in all core human rights instruments. In its General comment No. 5, the Committee on Economic, Social and Cultural Rights highlights that “segregation and isolation achieved through the imposition of social barriers” count as discrimination. It also stresses in relation to article 11 that the right to an adequate standard of living not only includes having equal access to adequate food, accessible housing and other basic material requirements, but also the availability of support services and assistive devices and technologies fully respecting the human rights of persons with disabilities.<sup>4</sup>

14. Article 19 and the content of this General comment must also be guiding and supporting the implementation of The New Urban Agenda (Habitat III) and as an integral part of 2030 Development Agenda and Sustainable Development Goals. The New Urban Agenda advocates a vision of cities and human settlements where all persons are enjoying equal rights and opportunities by promoting inclusive, just, safe, healthy, accessible, affordable, resilient and sustainable cities and human settlements. In connection with article 19 of the Convention, SDG target 10.2, empowerment and promotion of social, economic, political inclusion for all and target 11.1, ensuring access to adequate, safe and affordable housing and affordable services for all, are of special importance.

15. The Committee on the Rights of Persons with Disabilities has noted advancements in the past decade implementing article 19. However, the Committee observes a gap between the goals and spirit of article 19 and the scope of its implementation. Some of the remaining barriers are the following:

(a) Denial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements;

<sup>3</sup> Committee on the Rights of the Child General comment No. 9 (2006) The rights of children with disabilities, CRC/C/GC/9, 27 February 2007., para 47

<sup>4</sup> Committee on Economic, Social and Cultural Rights, General comment No. 5, para. 15 and paras. 48-49.



- (b) Inadequacy of social support and protection schemes for ensuring living independently within the community;
- (c) Inadequacy of legal frameworks and budget allocations aimed at providing personal assistance and individualized support;
- (d) Physical and regulatory institutionalization, including of children and forced treatment in all its forms;
- (e) Lack of deinstitutionalization strategies and plans and continued investments into institutional care settings;
- (f) Negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available assistance;
- (g) Misconceptions about the right to living independently within the community;
- (h) Lack of available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;
- (i) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of article 19, including the participation of representative organizations of persons with disabilities;
- (j) Insufficient mainstreaming of disability in general budget allocations; and
- (k) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within the community in a State party.

## II. Normative content of article 19

### A. Definitions

16. In the present General comment the following definitions apply:

(a) **Independent Living:** Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination is fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live, with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom, and does not necessarily mean living alone. It should also not be interpreted solely as the ability of carrying out daily activities by oneself. Rather, it should be regarded as the freedom to choice and control, in line with the respect for inherent dignity and individual autonomy, as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities.

(b) **Being included in the community:** The right to be included in the community relates to the principle of full and effective inclusion and participation in society as enshrined in, among others, article 3 (c) of the Convention. It includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them be fully included and participate in all spheres of social life. These services can, among others, relate to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media. The right also includes, having access to all measures and events of political and cultural life in the community, among others public meetings, sports events, cultural and religious festivals and any other activity in which the person with disability wishes to participate.

(c) **Independent living arrangements:** Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not “just” about living in a particular building or setting, it is, first and foremost, about losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although, institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: obligatory sharing of assistants with others and no or limited influence over by whom one has to accept assistance, isolation and segregation from independent life within the community, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control, however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of de-institutionalization therefore require implementation of structural reforms, which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family.

(d) **Personal assistance:** Personal assistance refers to person-directed/“user”-led human support available to a person with disability and it is a tool for independent living. Although modes of personal assistance may vary, there are certain elements, which distinguish it from other types of personal assistance, namely:

(i) **Funding** for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualised services must not result in reduced budget and/or higher personal payment;

(ii) **The service is controlled by the person with disability**, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, i.e. design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) **Personal assistance is a one-to-one relationship.** Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without full and free consent by the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community; and

(iv) **Self-management of service delivery.** Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the center of the decisions concerning the assistance, who must be enquired about and respected upon individual preferences. The control of personal assistance can be through supported decision-making.

17. Providers of support service often wrongly describe their support service by using the terms “independent” or “community living” as well as “personal assistance” though in practice such services do not fulfil the requirements posed by article 19. Mandatory “package solutions”, which among others link the availability of one particular service to another, expects to or more persons to live together, or can only be provided within special living arrangements. The concept of personal assistance where the person with disabilities does not have full self-determination and self-control are to be considered not compliant with article 19. Persons with complex communication requirements, including those who use informal means of communication (i.e. communication via non-representational means, including facial expression, body position and vocalisation) must be provided with appropriate supports enabling them to develop and convey their directions, decisions, choices and/or preferences, and have these acknowledged and respected.

## **B. Article 19, chapeau**

18. Article 19 reaffirms non-discrimination and recognition of the equal right of persons with disabilities to live independently in the community. In order for the right to live independently, with choices equal to others and be included in the community, to be realized, States parties must take effective and appropriate measures to facilitate the full enjoyment of the right and full inclusion and participation of persons with disabilities in the community.

19. The article covers two concepts, which are only clearly mentioned in its heading: the right to independent living and the right to be included in the community. Whereas the right to independent living refers to an individual dimension, as negative right to emancipate oneself without denials of access and opportunities, the right to be included in the community entail a social dimension, as positive right to develop inclusive environments. The right as enshrined in article 19 covers both concepts.

20. Article 19 explicitly refers to all persons with disabilities. Neither the full or partial deprivation of any “degree” of legal capacity nor level of support required may be invoked to deny or limit the right to independent and independent living in the community to persons with disabilities.

21. When persons with disabilities are assessed to be requiring high demands for personal service, States parties often consider institutions as the only solution, especially whether personal services are considered to be “too costly” or the person with disabilities as being “unable” to live outside institutionalised settings. Persons with intellectual disabilities, especially those with, complex communication requirements, inter alia, are often assessed as being unable to live outside of institutionalized settings. Such reasoning is contrary to article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirement.

22. All persons with disabilities should be free to choose to be active and belonging to cultures of their own choice, and they must have the same degree of choice and control over their lives as other members of the community. Independent living is not compatible with the promotion of “predefined” individual lifestyle. Young persons with disabilities should not be forced to live in settings designed for elderly persons with disabilities and vice versa.

23. Persons with disabilities of all genders are right-holders and enjoy equal protection under article 19. All appropriate measures should be taken to ensure the full development, advancement and empowerment of women. LGBTQI persons with disabilities must enjoy equal protection under Article 19 and therefore respect for their personal relationships. Furthermore, the right to live independently and be included in the community encompasses protection of persons with disabilities belonging to any age group, ethnic groups, scheduled castes, linguistic and/or religious minorities as well as migrant, asylum-seekers and refugee persons.

### **C. Article 19 (a)**

24. To choose and decide upon how, where and with whom to live is the central idea of the right to live independently and be included in the community. Individual choice, therefore, is not limited to the place of residence but includes all aspects of a person's living arrangements: daily schedule and routine as well as way of life and lifestyle of a person, covering private and public spheres in a daily and long term dimension.

25. Often, persons with disabilities cannot exercise choice because there is a lack of options to choose from. This is the case, for instance, whether informal support by the family is the only option, whether support is unavailable outside of institutions, whether housing is inaccessible or support is not provided in the community, and when support is only provided within specified forms of residence like group homes or institutions.

26. Further, persons with disabilities might not be allowed to exercise their individual choice due to the lack of accessible information regarding the range of choices available and/or due to legal restrictions deriving from guardianship laws and similar legal norms or decisions which do not allow persons with disabilities to exercise their legal capacity. Even if no formal laws are in place, others, like families, caregivers or local authorities, sometimes exercise control and restrict an individual's choices by acting as substitute decision-makers.

27. Legal personality and legal agency are the basis of the realization of independent living within the community for persons with disabilities. Article 19 is, therefore, linked to the recognition and exercise of legal personality and legal capacity as enshrined in article 12 of the Convention, and further explained in the Committee's general comment No. 1 (2014) on equal recognition before the law. Further, it is linked to the absolute prohibition of detention on the basis of disability as enshrined in Article 14 and elaborated in the respective guidelines<sup>5</sup>.

### **D. Article 19 (b)**

28. Individualised support services must be considered a right instead of a form of medical, social or charity care. For many persons with disabilities, access to a range of individualised support services is a precondition for independent living within the community. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences, and individualized support should be flexible enough to adapt to the "users'" requirements and not the other way around. This places an obligation on the States parties to ensure that there are sufficient number of qualified specialists who are able to identify practical solutions to the barriers to live independently within the community according to the requirements and preferences of the individual.

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<sup>5</sup> See Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities. Adopted during the Committee's 14th session, held in September 2015.

29. Subparagraph (b) specifies various individualised services, which fall within this category of support services. They are not restricted to services inside the home, but must also be able to extend to the spheres of employment, education or political and cultural participation, support services empowering parenthood and the ability to attend family relatives and others, participation in political and cultural life, once leisure interests and activities, and travel as well as recreation.

30. 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 be supporting living included within the community preventing isolation and segregation from others within the community and must in actuality be suitable to this purpose. It is important that the aim of these support services is the realization of full inclusion within the community. Therefore, any institutional form of support services, which segregates and limits personal autonomy, is not permitted by article 19 (b).

31. It is also relevant to keep in mind that all support services have to be designed and delivered in a mode, which supports the overall purpose of the norm: full, individualised, self-chosen and effective inclusion and participation and living independently.

## **E. Article 19 (c)**

32. Services and facilities mentioned in this section of the article are non-disability specific support services and facilities for the general population in the community. They cover a wide range of services, such as housing, public libraries, hospitals, schools, transport, shops, markets, museums, the Internet, social media and similar facilities and services. These must be available, universally accessible, acceptable and adaptable for all persons with disabilities within the community.

33. Accessibility of community facilities, goods and services, as well as the exercise of the right to inclusive accessible employment, education and health care are essential conditions for inclusion and participation of persons with disabilities in the community. Various de-institutionalization programs have shown that the closure of institutions, regardless of their size and the relocation of inhabitants in the community, in itself is not enough. Such reforms must be accompanied by comprehensive service and community development programs, including awareness programs. Structural reforms designed to improve overall accessibility within the community may reduce the demand for disability – specific services.

34. In terms of material scope, article 19 covers access to safe and adequate housing, individual services and community facilities and services. Access to housing means having the option to live in the community just like one is. Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighborhood. Accessible housing, providing accommodation to persons with disabilities, who live as singles or as a part of a family, must be available in sufficient number, within all areas of the community to provide the right and possibility for persons with disabilities to choose from. To this end, barrier-free residential new construction and the barrier-free retrofitting of existing residential structures are required. In addition, housing must be affordable to persons with disabilities.

35. Support services must be available within safe physical and geographical reach to all persons with disabilities living in urban or rural areas. They have to be affordable, taking into account persons living on low income. They also need to be acceptable which means that they must respect standard levels quality and be gender, age and culturally sensitive.

36. Individualised support services, which do not allow for personal choice and self-control are not providing for living independently within the community. Support services provided as combined residential and support service (delivered as a combined “package”) are often offered to persons with disabilities on the premise of cost efficiency. However, while this premise itself can be rebutted economically, aspects of cost efficiency must not

override the core of the human right at stake. Personal assistance and assistants should not be “shared” among persons with disabilities by rule, but only whether it is done with full and free consent of the person with disability requiring personal assistance. The possibility to choose is one of the three key elements of the right to live independently within the community.

37. The right to equal support services corresponds with the duty to ensure participation and involvement of persons with disabilities in processes related to facilities and services in the community, ensuring that they are responsive to specific requirements, gender and age sensitive, and that they are available to allow for spontaneous participation of persons with disabilities within the community. For children, the core of the right to live independently and be included in the community entails a right to grow up in a family.

## **F. Core elements**

38. The Committee finds it important to identify core elements of article 19 in order to ensure that the realization of a standardised minimum support level sufficient to exercise the right to live independently and be included in the community is incumbent upon every State party. States parties should ensure that core elements of article 19 are always respected, particularly in times of financial or economic crisis. These core elements are:

(a) To ensure the right to legal capacity, in line with the Committee’s general comment No. 1 (2014) on equal recognition before the law, to decide where, with whom and how to live to for all persons with disabilities, irrespective of impairment;

(b) Ensuring non-discrimination in accessing housing, including both income and accessibility and deciding upon mandatory building regulations securing new and renovated housing to become accessible;

(c) To develop a concrete action plan for independent living of persons with disabilities within the community, including take steps towards facilitating formal supports for independent living within the community so that informal supports by e.g. families is not the only option;

(d) To develop, implement, monitor and sanctioning non-compliance with legislation, plans and guidance on accessibility requirements for basic mainstream services to achieve societal equality, including participation by persons with disabilities within social media, and secure adequate ICT competence to secure that ICT development are protected and developed on the basis of universal design;

(e) To develop a concrete action plan and to take steps towards developing and implementing basic, personalized, non-shared and rights-based disability-specific support services and other forms of services;

(f) To ensure non-retrogression in achieving Article 19 unless they have been duly justified and in accordance with international law;

(g) To collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions; and

(h) To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.

## **III. Obligations of States parties**

39. The obligations of the States parties must reflect the nature of human rights as either absolute and immediate applicable (civil and political rights) or progressively applicable (economic, social and cultural rights). Article 19 (a), the right to choose one’s residence and

where, how and with whom to live, is immediately applicable as it is a civil and political right. Article 19 (b), the right to access individualised assessed support services, is an economic, social and cultural right. Article 19 (c), the right to avail service facilities, is an economic, social and cultural right, through that many mainstream services, such as accessible ICT technologies, websites, social medias, cinemas, public parks, theatres and sports facilities, serve both social and cultural purposes. Progressive realisation entails the immediate obligation to design and decide upon concrete strategies, plan of actions and allocate resources to develop support services as well as making existing as well as new general services inclusive for persons with disabilities.

40. The obligation to respect does not only include a negative aspect. Its positive aspect requires states to take all necessary measures to ensure that no rights enshrined in article 19 are violated by the State or by private entities.

41. In order to achieve the progressive realization of economic, social and cultural rights, States parties must take steps to the maximum of their available resources<sup>6</sup>. These steps must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means.<sup>7</sup> The systematic realization of the right to independent living in the community requires structural changes. In particular, this applies to de-institutionalization in all its forms.

42. States parties have the immediate obligation to enter into strategic planning with adequate timeframes and resourcing in close and respectful consultation with representative organizations of persons with disabilities to replace any institutionalized settings with independent living support services. The margin of appreciation of States parties is related to the programmatic implementation but not to the question of replacement. States parties should develop transitional plans in consultation directly with persons with disabilities, through their representative organisations in order to ensure full inclusion of persons with disabilities in the community.

43. When a State party seeks to introduce retrogressive measures on Article 19, for example, in response to economic or financial crisis, the State is obliged to demonstrate that such measures are temporary, necessary and non-discriminatory, and that the State party and the measures to respect its core obligations.<sup>8</sup>

44. The duty of progressive realization also entails a presumption against retrogressive measures in the enjoyment of economic, social and cultural rights. Such measures deprive people with disabilities of the full enjoyment of right to live independently and being included in the community. As a matter of consequence, retrogressive measures constitute a violation of article 19.

45. States parties are prohibited from taking retrogressive measures with respect to the minimum core obligations of the right to live independently within the community as listed in this general comment.

46. States parties are under immediate obligation to eliminate discrimination against individuals or groups of persons with disabilities and to guarantee their equal right to living independently and participation in the community. This requires States parties to repeal or reform policies, laws and practices that prevent persons with disabilities from, e.g. choosing their place of residence, access to affordable and accessible housing, from renting accommodation or from accessing general mainstream services facilities and services as their independence would require. The duty to provide reasonable accommodation (art. 5 (3)) is also not subjected to progressive realization.

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<sup>6</sup> See article 2 (1) of the Convention on Economic, Social and Cultural Rights and article 4 (2) of the Convention on the Rights of Persons with Disabilities.

<sup>7</sup> Committee on Economic, Social and Cultural Rights, General comment No. 3 para. 2.

<sup>8</sup> Letter of the Chair of the Committee to States parties on austerity measures, May 2012.

## A. Obligation to respect

47. The obligation to respect requires States parties to refrain from directly or indirectly interfering with or in any way limiting the individual exercise of the right to live independently and being included in the community. States parties should not limit or deny anyone access to living independently in the community, including through laws which directly or indirectly restrict the autonomy and options of persons with disabilities to choose their place of residence or where, how and with whom to live. States parties should reform laws that impede the exercise of the rights enshrined in article 19 of the Convention.

48. The obligation also requires States parties to repeal and refrain from enacting laws, policies and structures that maintain and create barriers in access to support services as well as general facilities and services. It also entails the obligation to release all individuals who are being confined against their will in mental health services or other disability-specific forms of deprivation of liberty. It further includes the prohibition of all forms of guardianship and the obligation to replace substituted decision-making regimes by supported decision-making alternatives.

49. To respect the rights of persons with disabilities under article 19 means that States parties need to phase out institutionalization. No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents' physical safety. Institutions should not be extended, new residents should not enter in place of those that leave, and "satellite" living arrangements that branch out from institutions, have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established.

## B. Obligation to protect

50. The obligation to protect requires States parties to take measures to prevent family members and third parties from directly or indirectly interfering with the enjoyment of the right to live independently within the community. The duty to protect requires States parties to put in place and implement laws and policies prohibiting conduct by family members and third parties, service-providers, landowners or providers of general services, which undermines the full enjoyment of the right to be included and be living independently within the community.

51. States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing, building existing and new institutions in any form of institutionalization. Furthermore, States parties must ensure that private institutions are not established in the guise of "community living".

52. Support should always be based on the individual requirements, not the interest of the service provider. States parties should establish monitoring mechanisms of service providers, adopt measures, which protect persons with disabilities from being hidden in the family or isolated in institutions, protect children from being abandoned or institutionalized on the grounds of disability and establish appropriate mechanisms to detect situations of violence against persons with disabilities by third parties. States parties should also prohibit that directors and/or managers of residential institutions become guardians of the residents.

53. The duty to protect also includes the prohibition of discriminatory practices, such as the exclusion of individuals or groups from the provision of certain services. States parties should prohibit and prevent third parties from imposing practical or procedural barriers to living independently and being included in the community, such as ensuring that services provided are in line with living independently in the community and that persons with disabilities are not denied the possibility to rent or are disadvantaged in the housing market. General community services open to the public such as libraries, swimming pools, public



parks/spaces, shops, post offices or cinemas must be accessible and responsive to the requirements of persons with disabilities, as enshrined in the Committee's general comment No. 2 (2014) Accessibility<sup>9</sup>.

### **C. Obligation to fulfill**

54. The obligation to fulfil requires States to promote, facilitate and provide appropriate legislative, administrative, budgetary, judicial, programmatic, promotional and other measures to ensure the full realization of the right to live independently and be included in the community as enshrined in the Convention. The obligation to fulfill also requires States parties to take measures to eradicate practical barriers to the full realization of the right to live independently and be included in the community, such as inaccessible housing, limited access to disability support services, inaccessible facilities, goods and services in the community and prejudices against persons with disabilities.

55. State parties should empower family members to support the family members with disabilities to realise their right to live independently and be included in the community.

56. While implementing legislation, policies and programs, States parties must closely consult and actively involve a diverse range of persons with disabilities through their representative organizations on all aspects concerning living independently in the community, in particular, when it comes to developing support services and investing resources in support services within the community.

57. States parties must adopt a strategy and a concrete plan of action for de-institutionalization. It includes the duty to implement structural reforms, to improve accessibility for persons with disabilities within the community and raising awareness among all persons in society about inclusion of persons with disabilities within the community.

58. De-institutionalization also requires a systemic transformation, which includes the closure of institutions and eliminating institutionalising regulations, as part of a comprehensive strategy. Along with establishment of a range of individualized support services, which include individualized plan for transition with budget and timeframe as well as inclusive support services. Therefore, a necessary coordinated, cross-government approach, which ensures reforms, budget and attitude on all levels and sectors of government, including local authorities is required.

59. Programs and entitlements to support living independently in the community must cover disability-related costs. Furthermore, ensuring the availability of sufficient number of accessible and affordable housing is crucial for de-institutionalization, including housing for families. It is also important that access to housing is not made conditional upon requirements that reduce autonomy and independence of persons with disabilities. Buildings and spaces open to the public and all forms of transport must be designed in a way to accommodate the requirements of all persons with disabilities. States parties must take deliberate and immediate steps to reallocate funding into realising the possibility of persons with disabilities to be living independently in the community.

60. Disability support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities and be sensitive to different living conditions, as e.g. individual or familiar income, and individual circumstances, such as sex, age, national or ethnic origin, linguistic, religious, sexual and/or gender identity. The human rights model of disability does not allow to exclude persons with disabilities upon any reason, including the kind and amount of support services required. Support services, including personal

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<sup>9</sup>[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en)

assistance, should not be shared with others unless it is based on a decision through free and informed consent.

61. States parties shall incorporate the following elements into the eligibility criteria for access assistance: The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment, take into account, and follow a person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process.

62. Cash transfers such as disability allowances represent one of the forms in which States parties provide support for persons with disabilities in line with articles 19 and 28 of the Convention. Such cash transfers often recognise disability-related expenses and facilitate the full to this to sleep of law and in any year earned inclusion of persons with disabilities in the community. Cash transfers also tackle situations of poverty and extreme poverty that persons with disabilities may face. States parties must not add to the hardship faced by persons with disabilities, by reducing their income in times of economic or financial crisis or through austerity measures that is inconsistent with human rights standards set out in paragraph 38, above.

63. Support for persons with disabilities should be assessed, through a personalised approach, and tailored to the specific activities and actual barriers that persons with disabilities face in being included in the community. The assessment should acknowledge that persons with disabilities require access to participate in activities that are varying over time. States parties should ensure that personalization of support, including cash transfers/personal budgets, take into account and address the challenges that persons with disabilities face when living in rural and/or urban areas.

64. States parties should provide and disseminate timely up to date and accurate information essential for informed decision-making on choices of independent living and support services in the community in accessible formats, including braille, sign language, tactile, Easy Read formats and alternative and augmentative modes of communication.

65. States should ensure that personnel working or on the step to enter working in disability-related services including staff, decision-makers and civil servants monitoring services for persons with disabilities, are adequately trained on independent living within the community, in theory and practice. States also should establish criteria in line with article 19, concerning entities applying for being allowed to deliver social support for persons with disabilities to live in the community, and assess how they perform their duties.

66. States parties should also ensure that international cooperation in accordance with article 32 and the following investments and projects do not contribute to the perpetuation of barriers to independent living within the community but rather eradicate barriers and support the implementation of the right to live independently and be included in the community. After situations of disaster, it is important not to rebuild barriers, as an element of implementing article 11 of the Convention.

67. States parties must ensure access to justice and provide legal aid, appropriate legal advice, remedies and support, including through reasonable and procedural accommodation for persons with disabilities who seek to enforce their right to living independently in the community.

68. States parties should provide adequate support services to family carers, so they can in turn support their child or relative to live independently in the community. This support includes respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers who often live in situations of extreme poverty, without the possibility of accessing the labour market. States parties should also provide social support to families and foster the development of counselling services, circles of support and other adequate support options.

69. States parties must regularly conduct surveys and other forms of analysis providing data on the physical, communicative, environmental, infrastructural and attitudinal barriers experienced by persons with disabilities and the requirements for implementing living independently in the community.

#### **IV. Relationship with other provisions of the Convention**

70. The right to live independently and be included in the community is interrelated with the enjoyment of other human rights provided for in the Convention. At the same time, it is more than the sum of those rights as it affirms that all rights should be exercised and enjoyed in the community where a person chooses to live and in which alone the free and full development of one's personality can be fulfilled.

71. Consultations with and active involvement of persons with disabilities, through their representative organizations (art. 4 (3)) is critical for the adoption of all plans and strategies as well as for the follow-up and monitoring when implementing the right to independent living in the community. Decision-makers at all levels must actively involve and consult the full range of persons with disabilities including organizations of women with disabilities, older persons with disabilities, children with disabilities, persons with psychosocial disabilities, and persons with intellectual disabilities.

72. Non-discrimination (art. 5), in terms of living independently and being included in the community is important in regard to accessing and receiving support services. States parties should define eligibility criteria and procedures for accessing support services in a non-discriminatory way, objectively and focused on the requirements of the person rather than the impairment, following a human rights-compliant approach. The establishment of specific services for persons with disabilities in the particular circumstances of the persons with disabilities and in accordance with their requirements, such as services for children, students, employees and older persons with disabilities, should not be considered as a discriminatory violation of the Convention, but rather as a just and legally available affirmative action. Persons with disabilities who face discrimination in relation to article 19 must have effective and affordable legal remedies at their disposal.

73. Often, women and girls with disabilities (art. 6) are more excluded and isolated, and face more restrictions regarding their place of residence as well as their living arrangements due to paternalistic stereotyping and patriarchal social patterns against women in society. Women and girls with disabilities also experience gender-based, multiple and intersectional discrimination, institutionalization, violence, including sexual violence abuse and sexual harassment<sup>10</sup>. States Parties must provide affordable, or free legal remedy and support services for victims of violence and abuse. Women with disabilities who face domestic violence are frequently more economically, physically, or emotionally dependent on their abusers, who often act as caregivers, a situation that prevents women with disabilities from leaving abusive relationships and leads to further social isolation. Therefore, when implementing the right to live independently and be included in the community, particular attention should be paid to gender equality, the elimination of gender-based discrimination and patriarchal social patterns.

74. Cultural norms and values may adversely restrict the choices and control of women and girls with disabilities over their living arrangements, limit their autonomy, oblige them to live in particular living arrangements, require them to suppress their own requirements and instead serve those of others and take certain roles within the family.<sup>11</sup> States parties should take measures to tackle discrimination and barriers against women in accessing social services and support, as well as ensure that various policies, programmes and

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<sup>10</sup> See Committee on the Rights of Persons with Disabilities, General comment No. 3 (2016) Women and Girls with Disabilities.

<sup>11</sup> Ibid. paras. 8, 18, 29, and 55.

strategies concerning access to social services and support take due consideration of the equality between women and men.

75. States parties should also ensure that measures aimed at development, empowerment and advancement of women and girls with disabilities (article 6 (2)), address gender-based inequalities in accessing support and social protection. States Parties should adopt adequate work-life balance measures (resources, time, services) that support women with disabilities in (re-)entering the open labour market and ensure equal rights and responsibilities between women and men for the exercise of parental responsibilities<sup>12</sup>. It is also the responsibility of the State parties to ensure that shelters for victims of gender-based violence are fully accessible to women and girls with disabilities.

76. The existence of adequate and age-sensitive support services for girls and boys with disabilities is of vital importance for equal enjoyment of their human rights (art. 7). Respecting the evolving capacities of children with disabilities and supporting them in having a say on choices that impact them is critical. It is also important to provide support, information and guidance to families (art. 23) to prevent institutionalization of children with disabilities and to have inclusive policies on adoption to ensure equal opportunities to children with disabilities.

77. When it comes to social interactions and relationships with peers, teenagers may prefer personal assistance or professional sign language interpreters to informal support provided by relatives. States parties should establish innovative forms of support and accessible services for children and adolescents with disabilities personally or through their organisations. Children with disabilities may require support to practice sports or activities in the community according to their age. Adolescents with disabilities should be enabled to spend time and take part in leisure activities with their age peers. States parties must provide assistive devices and technologies that can facilitate the inclusion of adolescents with disabilities in their peer networks. Further, services that facilitate the transition of young people into adulthood, including support with moving out of the family home, starting employment, and continuing into higher education are crucial in supporting independent living.

78. Awareness-raising (art. 8) is essential to create open, enabling and inclusive communities as article 19 ultimately is about transforming communities. Stereotypes, ableism and misconceptions that prevent persons with disabilities from living independently must be eradicated and their positive image and contributions to society must be promoted. Awareness-raising should be provided for authorities, civil servants, professionals, the media, the general public and persons with disabilities and their families. All awareness-raising activities should be carried out in close cooperation with persons with disabilities through their representative organizations.

79. The rights provided for in article 19 are tied to the obligations of the States parties relating to accessibility (art. 9) because the general accessibility of all built environment, transport, information, communication and facilities and services open to the public in a respective community is a precondition for living independently in the community. Article 9 requires the identification and elimination of barriers in buildings open to the public, such as the revision of building control acts and urban planning codes, the inclusion of standards of universal design in a variety of sectors, and the establishment of accessibility standards for housing.

80. States parties must take into account in advance the obligation to provide support services to persons with disabilities in all disaster risk management activities (art. 11) and make sure they are not left behind or forgotten. It is also important that barriers are not rebuilt after situations of armed conflict, humanitarian emergencies or the occurrence of

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<sup>12</sup> Committee on the Elimination of Discrimination against Women. General Recommendation No. 21 (13th session, (1994) Equality in marriage and family relations

natural disasters. Reconstruction processes must ensure full accessibility for the independent life in the community of persons with disabilities.

81. Equal recognition before the law (art. 12) ensures that all persons with disabilities have the right to exercise their full legal capacity and therefore have the equal right to choose and control over their own lives by choosing where, with whom and how they want to live and to receive support according to their will and preferences. To fully realize the transition to supported decision-making and implement the rights enshrined in article 12, it is imperative that persons with disabilities have the opportunity to develop and express their will and preferences in order to exercise their legal capacity on an equal basis with others. To achieve this, they have to be a part of the community. Furthermore, support in the exercise of legal capacity should be provided by using a community-based approach, which respects the will and preferences of individuals with disabilities.

82. Access to justice as enshrined in article 13 is fundamental to ensure full enjoyment of the right to live independently in the community. States parties must ensure that all persons with disabilities have legal capacity and standing in courts. States parties must furthermore ensure that all decisions concerning living independently in the community may be subject to appeal. Support to enable living independently in the community shall be enforceable as rights and entitlements. To ensure equal and effective access to justice substantial rights to legal aid, support and procedural and age-appropriate accommodations are essential.

83. Involuntary institutionalization on the basis of impairment or associated circumstances such as presumed “dangerousness” and other factors as elaborated in the Committee’s guidelines on article 14 is often caused or increased by a lack of disability specific support services. Implementing article 19 thus will ultimately prevent violation of article 14.

84. It is of paramount significance to ensure that support services leave no space for potential abuse, exploitation of persons with disabilities or any violence against them (art. 16). Disability, gender and age-sensitive monitoring, legal remedies and relief must be available for all persons with disabilities who use services prescribed in article 19 and who may face abuse, violence and exploitation. Since institutions tend to isolate those who reside within them from the rest of the community, institutionalized women and girls with disabilities are further susceptible to gender-based violence, including forced sterilization, sexual and physical abuse, emotional abuse and further isolation. They also face increased barriers to reporting this violence. It is imperative that states include these issues in their monitoring of institutions and ensure access to redress for women with disabilities who are exposed to gender-based violence in institutions.

85. Without support of personal mobility (art. 20), barriers to living independently in the community continue to exist for many persons with disabilities. The provision of affordable and available quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries as enshrined in article 20 is a pre-condition for the full inclusion and participation of persons with disabilities in their respective communities.

86. Persons with disabilities have the right to access all public information in accessible formats and to seek, receive and express information and ideas on an equal basis with others (art. 21). Communication can be provided in forms and formats of their choice, including Braille, sign language, tactile, Easy Read formats and alternative modes, means and formats of communication. It is important that communication and information can flow in both directions, and that services and facilities are accessible for individuals who use different ways of communication. It is of particular importance that information about support services and social protection schemes, including disability related mechanisms, is accessible and available from a diversity of sources in order to enable persons with disabilities to make fully informed decisions and choices about where, with whom and how to live and what kind of service is best suited. It is also of critical importance that mechanisms to provide feedback and complaints are communication accessible.

87. States parties should ensure that in the provision of support services under article 19, the privacy, family, home, correspondence and honour of persons with disabilities are protected from any unlawful interference (art. 22). In any case of unlawful interference, disability, gender and age-sensitive monitoring, legal remedies and relief must be available for all persons with disabilities using support of services.

88. The right to living independently in the community is intimately linked with the right to family for children and parents with disabilities (art. 23). If community based support and services are not in place, this may create financial pressures and constraints for the family of persons with disabilities; the rights enshrined in article 23 of the Convention are essential to prevent children from being taken away from their families and being institutionalized as well as to support families in community living. These rights are equally important to ensure that children are not taken away from their parents due to the latter's disability. States parties should provide information, guidance and support to families in upholding their children's rights and promote inclusion and participation in the community.

89. Living independently and being included in the community is inherently linked to inclusive education (art. 24), requires recognition of the right of persons with disabilities to live independently and enjoy inclusion and participation in the community.<sup>13</sup> Inclusion of persons with disabilities in the mainstream education system generates further inclusion of persons with disabilities in community. De-institutionalization also entails the introduction of inclusive education. States parties should note the role that exercising the right to inclusive education will play in building the strengths, skills and competencies necessary for all persons with disabilities to enjoy, benefit from and contribute to their communities.

90. General health facilities and services (art. 25) must be available, accessible, adaptable and acceptable for persons with disabilities in their communities, including and welcoming the support required by some persons with disabilities (with complex communication requirements, psychosocial disabilities, intellectual disabilities and/or deaf persons) during hospitalizations, surgeries, and medical consultations. The provision of nurses, physiotherapists, psychiatrists or psychologists in hospitals as well as at home, is a part of health care and should not be seen as the fulfilment of a States parties' obligation under article 19 but under article 25.

91. There is interdependence between independent living in the community, habilitation and rehabilitation (art. 26). For some persons with disabilities, participation in rehabilitation services is not possible if they do not receive sufficient individualized support. At the same time, the purpose of rehabilitation is to enable persons with disabilities to fully and effectively participate in the community. The habilitation and rehabilitation of a person with disability must always respect his/her free and informed consent. Habilitation and rehabilitation is dominantly relevant in relation to education, employment, health and social matters.

92. The existence of individualised support services, including personal assistance, often is a pre-condition for effective enjoyment of the right to work and employment (art. 27). Furthermore, persons with disabilities should also become employers, managers or trainers in disability specific support services. Implementing article 19 will thus help to phase out sheltered employment.

93. To ensure that persons with disabilities enjoy an adequate standard of living (art. 28), States parties should provide, inter alia, access to support services that enable them to live independently. Therefore, there is an obligation on the part of States parties to ensure access to appropriate and affordable services, devices and other assistance for impairment-related requirements, especially for those persons with disabilities who live in poverty.

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<sup>13</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 4 (2016) Right to inclusive education.

Furthermore, access to public and subsidized housing programs in the community is required. It is considered contrary to the Convention if persons with disabilities are supposed to pay for disability-related expenses by themselves.

94. In order to influence and take part in decisions impacting the development of their community, all persons with disabilities should enjoy and exercise their rights to participation in political and public life (art. 29) personally or through their organisation. Appropriate support can provide valuable assistance to persons with disabilities in exercising their right to vote, to take part in political life and to conduct public affairs. It is important to ensure that assistants or other support staff do not restrict or abuse the choices that persons with disabilities make in exercising their voting rights.

95. Cultural life, recreation, leisure and sports (art. 30) are important dimensions of life in the community in which inclusion can be pursued and achieved, for example by ensuring that events, activities and facilities are accessible to persons with disabilities and inclusive. Personal assistants, guides, readers, professional sign language and tactile interpreters, amongst others, contribute to an inclusive life in the community according to the will and preferences of persons with disabilities. It is important that the use of support of any kind is considered part of disability-related expenses since such support services help foster inclusion in the community and independent living. Assistants necessary for participating in cultural and leisure activities should be free of paying entrance. There also should not be restrictions on when, where and for what kind of activities to use the assistance, nationally and internationally.

96. Data and information must be disaggregated systematically (art. 31) by disability across all sectors including with respect to housing, living arrangements, social protection schemes as well as access to independent living and support and services. The information should allow for regular analyses on how de-institutionalization and transition to support services in the community have progressed. It is important that indicators reflect the particular circumstances in every State party.

97. International cooperation (art. 32) must be conducted in a way which ensures that foreign aid is invested in support services in local communities that respect the will and preferences of persons with disabilities and foster their right to choose where, with whom and under which living arrangements they will live, in line with article 19. Investing money obtained in the framework of international cooperation into development of new institutions or places of confinement or institutional models of care is not acceptable as it leads to segregation and isolation of persons with disabilities.

## **V. Implementation at the national level**

98. The Committee notes that States parties may face challenges at the national level when implementing the right to living independently and being included in the community. However, in line with the normative content and obligations outlined above, States parties should take the following steps to ensure the full implementation of article 19 of the Convention:

(a) Repeal all laws that prevent any person with disabilities, regardless of type of impairment, to choose where and with whom and how to live, including the right not to be confined on the basis of any kind of disability;

(b) Enact and enforce laws, standards, and other measures with the purpose to make local communities and environment as well as information and communication accessible to all persons with disabilities;

(c) Ensure that social protection programs meet the requirements of the diverse range of persons with disabilities on an equal basis with others;

(d) Insert the principle of universal design for both physical and virtual space in policies, law, standards and other measures, including monitoring the

realization/implementation of the obligations. Review their building codes in order to comply with principles of universal design and legislative guidelines on construction as outlined in the Committee's general comment No. 2 (2014) Accessibility;

(e) Provide all persons with disabilities with substantive and procedural rights to be living independently within the community;

(f) Inform persons with disabilities about their right to live independently and be included in the community in ways they can understand and provide empowerment trainings with the aim that persons with disabilities learn how to enforce their rights;

(g) Adopt clear and targeted strategies for de-institutionalization with specific timeframes and adequate budgets in order to eliminate all forms of isolation, segregation or institutionalization of persons with disabilities. Special attention should be paid to persons with psychosocial and/or intellectual disabilities and children with disabilities currently in institutions;

(h) Create awareness that tackle negative attitudes and stereotypes about persons with disabilities and secure community transformation in an effort to develop individualized and accessible mainstream services;

(i) Ensuring participation of persons with disabilities, personally and through their representative organizations, is pivotal in transforming support services and communities, and in the design and implementation of de-institutionalization strategies;

(j) Design comprehensive policies and legislative guidelines and allocate financial resources for the construction of affordable and accessible housing units, built environment, public spaces and transport along with an adequate time frame for their implementation and sanctions which are effective, deterrent and proportionate for violations by public or private authorities;

(k) Allocate resources into the development of appropriate and sufficient person-directed/"user"-led and self-managed support services for all persons with disabilities, such as personal assistance, guides, readers, professional sign language or interpreters;

(l) Design tendering processes concerning support services for persons with disabilities' living independently in the community that take into account the normative content of Article 19;

(m) Establish mechanisms to monitor existing institutions and residential services, de-institutionalization strategies and the implementation of living independently within the community, bearing in mind the role of the independent monitoring frameworks; and

(n) Monitoring and implementation envisaged under article 19 should be carried out in full consultation and participation of persons with disabilities through their representative organizations.