立法會福利事務委員會

2020年9月23日 特別會議

照顧者支援及殘疾人士住宿照顧服務

香港殘疾人權利聯盟 意見書

殘疾兒童及成人和其家長/照顧者的需要與其他香港人一樣的:

要有尊嚴的生活:

要有家居生活:在家、在學、在職、在社區,有不同的人際關係一生有學習、有工作、有餘暇、有社交、有分享、有貢獻最重要的是在生命不同階段,

要有夢想,有朋友圈子、支援網絡、不同生活方式 **要有個人選擇 、 生活要有不同經驗**、有個人故事 是香港公民,而不是機構的個案 、社會的問題 ¹

香港開埠以來,由 1863 年教會成立第一間視障人士宿舍, 到近期小欖醫院重建的可住超過 1,100 位殘疾人士的大型院舍 香港政府的「康復」觀念和服務模式,對殘疾人士及其照顧者的支援仍然是以 70 年代補鑊、補底的原則,服務既單一、又有選擇。²

其實在2008年8月香港已是《殘疾人權利公約》(下稱《公約》)的締約城市,

香港政府是有責任要訂定時間表按《公約》的原則去修訂所有法例、政策、服務和措施,當 全世界大部分先進國家和《公約》締約國都已摒棄監護及院舍制度,尤其是對智障成人,仍 是用大型院舍、醫療角度去箝制他們的自主決策權利,政府仍以保護為名去剝奪智障人士的 家庭生活權利和自立生活的權利,獲取通達資訊和技能的權利!

香港的社會服務發展,尤其是殘疾人士的服務發展,除了違反了多項國際人權公約的原則和 標準外,更加是完全大倒退!

香港殘疾人權利聯盟建議所有為殘疾人士支援和照顧及照顧者支援的法例、政策、服務和措施的檢討、計劃、執行和監察都要按《殘疾人權利公約》、《兒童公約》和《<u>禁止</u>酷刑公約》和《公約》委員會的審議報告建議、條例說明(附件)去規劃和實踐。其實所有《公約》的原則和建議是要政府有責任確保全港市民的基本人權,絕非理想得遙不可及!

就照顧者支援及殘疾人士住宿照顧服務這議題應改為殘疾人士居住支援和照顧及照顧者支援

因為殘疾人士及其照顧者的支援及照顧服務要有多元選擇,居住不一定在院舍,即使居於院舍,亦要有按個不同需要的度身而設的支援。

我們要求:

- 1. 立即成立全天候24小時緊急支援服務隊,上門支援居家輪候宿舍的兒童和成人。
- 2. 疫症隔離期間,要增加資源開展疫期,要留家/留院/限聚的創新服務模式。
- 3. 為所有居於特殊學校宿舍的畢業生離校準備:
- 3.1 做社區生活評估機制,以家庭為本,為畢業生及其照顧者做全面離校適應支援需要和 風險評估。
- 3.2 要提供以家庭為本、尊重智障成人身份的無縫銜接 24 小時社區支援服務。
- 3.3 教育局和社會福利署要立即為現時制度做檢討、跟進和改善計劃:
 - 1) 法團校董會的權責?
 - 2) 學校社工與宿舍舍監(社工)的分工、誰是主案社工?
 - 3) 居於宿舍的學童、準畢業生回家生活和家人相處的支援為何?
 - 4) 畢業生(已屆成人),不論有否輪候院舍,要離校回家與家人同住,有否有居家和社區 生活適應需要評估及相關支援服務?
 - 5) 誰提供成人服務資訊給畢業生及其家人?
 - 6) 畢業生要離校回家與家人同住,誰提供的上門居家和社區生活適應?
- 3.4 做檢討和計劃時成年智障人士要有倡導者和家長一同參與

4. 建立社區為本的殘疾事務辦事處、設立全納通達支援網絡和服務:

- 4.1 區議會和房屋署發展好鄰舍社區支援網絡
- 4.2 十八區/公、私營屋苑建立通達服務中心、網上資訊和溝通平台
- 4.3 發展主流服務殘疾主流化,建立全納通達服務
- 4.4 所有公共屋邨設有居住單位供成年智障人士入住

5. 發展《殘疾人權利公約》角度的智障成人生活在家居和社區支援:

- 5.1 要有終身的牛涯規劃服務
- 5.2 智障成人居家生活要有獨立的經濟支援 (即可獨立申請綜援或低收入津貼)
- 5.3 要有24小時生活支援,保障智障成人生活自主,减輕其家人照顧的責任和壓力
- 5.4 要有照顧者政策、服務和措施,一定要以個別家庭的需要作規劃

- 5.5 要有成人倡議制度,凡 18 歲或以上的智障成人都享有成人倡議服務, 保障其尊嚴和人權
- 5.6 要發展決策支援服務,有不同形式決策支援,保障智障人士自主自決的權利
- 5.7 要為在社區居住又在輪候宿舍的家庭提供到戶生活支援和購買服務的費用
- 5.8 要有創意、有彈性去發展以智障人士個人及其家庭的社區支援服務
- 5.9 所有服務要提供易讀、簡易圖文版,保障智障人士及其家人的知情自決的權利
- 5.10 做檢討和計劃時要有家長和智障人士自及其倡導者參與

6. 香港是《殘疾人權利公約》締約地區,政府各部門有切實執行《公約》的義務:

- 6.1 要還所有受障人士法律人格和成人身份:
 - 政府要定時間表及成立工作小組修改現在有違《公約》的法例、政策和服務模式
- 6.2 要定時間表、邀請智障人士、其倡導者和家長/照顧者以《公約》原則去檢討和計劃
- 6.2 教育、醫療和社會福利要改革,教育專業人士、家長、智障人士有自立生活的觀念和準備
- 6.3 要尊重智障人士社區生活權利 和 尊重家居和家庭 《公約》第十九條、第二十三條3
- 6.4 要尊重智障人士自主決策權利 《公約》第十二條
- 6.5 政府要撥款成立獨立部門/機構 **殘疾事務和人權監察局去監察**各政策和部門 執行《公約》及其他國際人權公約的成效

敬請各位政府官員、議員、學者、專業人士能夠認真參考不同《公約》

請大家更新觀念,更加要全面更新服務模式

不要再用智障人士的生命,來推政策和服務的少修少補

請大家要以權利角度來改革社會服務

建立全納社區

區艷芳 23.9.2020

參考資料

註 1. 殘疾人士的生活與服務

Education 教育	Therapy 治療	Living a life 生活
School 學校	Day Treatment 日間治療	Home-Work-Soc/Leis
		家居-工作-社交/餘暇
Classes 班	Group 小組	Relationships 關係
Class Period 課堂	Session 節	Stage/Passages 階段
Teaching (Teachers) 教(教師)	Therapy (Therapist)	Experiences 經驗
	治療(治療師)	
Team Teaching 團隊教育	Inter-DiscplinaryTeam 跨專業團	Circle of Friends 朋友圈子
Students 學生	Clients/Patients 案主/病人	Citizen (Neigh.,Men.) 公民
Approach 方法	Treatment Modality 治療程式	Support circle 支援網絡
Expectations 期望	Prognosis 預知	Dreams 夢想
Curriculum 課程	Prescription 處方	Lifestyle 生活方式
Enrolment 登記	Admission 錄取	Birth 生
Graduation 畢業	Discharge 離開	Death 死
School Environ. 校舍	Milieu 相關場所	Community Places 社區
Term 學期	Length of Stay 療程	Lifetime 一生
Learning 學習期	Therapeutic 治療性	Sharing-Contributing
		分享/貢獻
IEP 個別教育計劃	IHP/ITP 個別康復/個別訓練計劃	PCP 個人選擇
Records/Files 記錄/檔案	Records/ Files 記錄/檔案	Stories 個人故事

I live my life but NOT an object of the service model

※ Note: Living a Life is not a service Model

註: 社區不是一種模式,祇作了解分項比較參考

註 2. 殘疾人運動發展

年代	世界發展	香港發展	
114	野孩子 Itard	1863 年 嘉諾撒修院(Canossian Sisters)成立	
	特殊教育的開始	第一間視障人士宿舍	
	首間院舍: Dr. Samuel Home		
40	智商介定的開始:	1938年 為殘疾人士提供臨時住宿的營舍	
	優生學說	於馬頭涌設立,	
		1949 年 遷往北角營舍。	
50		1955 年前 智障兒童安放於醫院	
	家長運動		
60	自我倡導運動	1964年 社會福利署香港仔傷殘重建院	
	常態化	(前身為北角營舍)開幕 (東華三院綜合大樓現址)	
		新生會亦在私人 700 呎樓開始了第一間中途宿舍,	
		三層床,共住 19 人	
70	去院舍化	1976年 首個《康復計劃方案》英國議員有份起草	
	社區自立生活	1977年《群策群力協助弱能人士更生》白皮書	
	尊人運動	(醫療模式服務規劃) 跨部門、跨專業	
80	社區生活、公民參與	日間服務、院舍	
	輔助就業、個人服務	家長組織	
		10.1988年 《禁止酷刑公約》在港生效	
90	全融社區		
90	主殿11 四 自我倡導	3.1992年 《兒童公約》在港生效	
		 1995 年《平等齊參與・展能創新天》白皮書	
		(醫療模式服務規劃) 傷健共融 在社區	
		家長資源中心	
		MAY DEMINISTRATION IN IN A VISA	
2000	 個人生活助理	資助自助組織	
	殘疾人權利公約	2007年 《康復計劃方案》檢討	
		(醫療及社會模式服務規劃)	
	權利為本去制定		
	法律、政策、服務、措施	8.2008年 《殘疾人權利公約》 在港生效	
		2009年 地區支援中心	
		2020年 《殘疾人及香港康復計劃方案》	
		(醫療及社會模式服務規劃)	

註 3. 殘疾人權利公約

第十九條 獨立生活和融入社區

本公約締約國確認所有殘疾人享有在社區中生活的平等權利以及與其他人同等的 選擇,並應當採取有效和適當的措施,以便利殘疾人充分享有這項權利以及充分融入 和參與社區,包括確保:

- (一) 殘疾人有機會在與其他人平等的基礎上選擇居所,選擇在何處、與何人一起 生活,不被迫在特定的居住安排中生活;
- (二) 殘疾人獲得各種居家、住所和其他社區支助服務,包括必要的個人援助,以 便在社區生活和融入社區,避免同社區隔絕或隔離;
- (三) 殘疾人可以在平等基礎上享用為公眾提供的社區服務和設施,並確保這些服務和設施符合他們的需要。

第二十三條

尊重家居和家庭

- 一. 締約國應當採取有效和適當的措施,在涉及婚姻、家庭、生育和個人關係的一切事項中,在與其他人平等的基礎上,消除對殘疾人的歧視,以確保:
- (一) 所有適婚年齡的殘疾人根據未婚配偶雙方自由表示的充分同意結婚和建立家 庭的權利獲得承認;
- (二) 殘疾人自由、負責任地決定子女人數和生育間隔,獲得適齡資訊、生殖教育和計劃生育教育的權利獲得承認,並提供必要手段使殘疾人能夠行使這些權利;
 - (三) 殘疾人,包括殘疾兒童,在與其他人平等的基礎上,保留其生育力。
- 二. 如果本國立法中有監護、監管、託管和領養兒童或類似的制度,締約國應當確保殘疾人在這些方面的權利和責任;在任何情況下均應當以兒童的最佳利益為重。 締約國應當適當協助殘疾人履行其養育子女的責任。
- 三.締約國應當確保殘疾兒童在家庭生活方面享有平等權利。為了實現這些權利,並為了防止隱藏、遺棄、忽視和隔離殘疾兒童,締約國應當承諾及早向殘疾兒童 及其家屬提供全面的資訊、服務和支助。
- 四.締約國應當確保不違背兒童父母的意願使子女與父母分離,除非主管當局依 照適用的法律和程式,經司法覆核斷定這種分離確有必要,符合兒童本人的最佳利 益。在任何情況下均不得以子女殘疾或父母一方或雙方殘疾為理由,使子女與父母分 離。
- 五. 締約國應當在近親屬不能照顧殘疾兒童的情況下,盡一切努力在大家庭範圍 內提供替代性照顧,並在無法提供這種照顧時,在社區內提供家庭式照顧。

	Article 12 – Illustrative indicators on equal recognition before the law		
Attailants /	Right to recognition everywhere as equal before the law		
Attributes/ Indicators	Universal legal capacity*	Supported decision-making**	Safeguards on the provision of support
Structure	12.1 Legislation enacted that:	12.3 Legislation enacted that:	
Structure	 recognises the capacity of persons with disabilities to create, modify and end legal relationships on an equal basis with others; protects the right and exercise of legal capacity of persons with disabilities against interference in all aspects of life; abolishes all forms of substitute decision-making; requires public and private actors to respect the individual's exercise of legal capacity at all times; provides prompt and effective remedies to overturn and redress any restriction in law or in practice of an individual's legal capacity or failure to respect their decision-making on the basis of actual or perceived impairment. 12.2 No provision in legislation or regulations that: restrict the legal capacity of persons with disabilities on the basis of actual or perceived impairment; restrict the enjoyment and exercise of legal capacity on the basis of actual or perceived impairment with respect to any right; Limit or deny access to court of persons with disabilities including for the purposes of invoking restoration of legal capacity. 	preferences and is made available to all persons; ensures that informal and formal support arrangements are available, accessible, adequate and permit the creation and implementation of various supported decision-making schemes; recognises the support person(s) and support arrangement by the individual requesting support; for formal arrangements, establishes a mechanism to verify the identity of the support person(s) to challenge the actions of support person(s) if alleged not to be in accordance with the individual's will & preferences; includes advance planning for support and decision-making, in which the individual concerned defines the moment in which an advance directive enters into force and ceases to have effect; provides for the right to refuse/modify a support relationship; provides safeguards against conflicts of interest, undue influence and abuse of support arrangements and ensures that the support provided respects the rights, autonomy, will and preferences of the individual requesting support, with remedies for violations and regular reporting and evaluation of support mechanisms in consultation with concerned groups; abolishes the concept of "best interests" in the determination of the type and extent of support provided to persons with disabilities; ensures accessibility and the duty to accommodate in all contexts requiring an exercise of legal capacity; allows for interpretation of the person's will and preferences exclusively in cases when it has not been possible, following significant efforts to determine them using diverse methods of communication.	
	location, migrant status, minority/indigenous background, etc.	ed of legal capacity and restoration of legal capacity, disaggregated by sex other educational institutions) on the right to legal capacity of persons v	
Process		12.8 Quality standards for supported decision-making adopted cover modification/termination of support in accordance with the individua support. xi 12.9 Budget allocated and spent on programmes to provide supported depersons with disabilities. xii 12.10 Research and development is undertaken, xiii to explore, define an and constituencies, in close consultation with that population and their activity. 12.11 Number of functioning programmes and services providing disaggregated by the type and intensity of support, and number of benefor residence xiv and geographic location. xv 12.12 Number of persons trained to provide support in decision-main individual's will and preferences, including on advance planning. 12.13 Number of persons having made advance plans in accordance with age, disability, and matters covered by the advance plan. xvi 12.14 Existence of mechanisms and procedures for the monitoring of for the participation of persons with disabilities, including through their process. with disabilities, notaries, judges and court staff, health care providers, finar unities) about the right to legal capacity of persons with disabilities and right.	ecision-making for the exercise of legal capacity of and meet the needs of diverse impairment groups or representative organizations in all stages of the a broad range of person-centric support with ficiaries disaggregated by sex, age, disability, place king for persons with disabilities respecting the h their will and preferences, disaggregated by sex, amal or informal support arrangements that ensure representative organizations, in the monitoring incial service providers and other actors involved in
	12.16 Number and proportion of judges, notaries and other legal profession.12.17 Consultation processes undertaken to ensure the active involved.	unities) about the right to legal capacity of persons with disabilities and right professionals trained on the right to legal capacity of persons with disable ement of persons with disabilities, including through their representative equal recognition before the law, and supported decision making and safeg	bilities and right to support for decision-making, organizations, in the design, implementation and

	12.18 Proportion of received complaints alleging restrictions to the exercise of legal capacity, either in law or in practice, or other violations of Article 12 of the CRPD that have been investigant and adjudicated; proportion of those found in favour of the complainant; and proportion of the latter that have been complied with by the government and/or duty bearer (e.g. private scent disaggregated by kind of mechanism.	
Outcomes	12.19 Number of persons with disabilities formally deprived of their legal capacity (either fully or partially), xix disaggregated by sex, age, and disability.	
	12.20 Number of persons with disabilities whose full legal capacity has been restored, disaggregated by sex, age and disability. 12.21 Number of persons who formally requested support for decision-making and the proportion who received it, disaggregated by sex, age, disability, and type/duration of support received.	

12.22 Number and proportion of persons with disabilities reporting that their requirements for supported decision-making have been met, disaggregated by sex, age, disability,

ANNEX

*Universal legal capacity encompasses the enjoyment and exercise of legal capacity on an equal basis with others. See CRPD Committee's General Comment no. 1, report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/37/56, paras. 13-22.

**"Support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. It should encompass a range of measures which respond to different situations and the choices of different individuals. One individual may choose to make use of several different support arrangements which work in complementarity. Support arrangements may consist of choosing one or more trusted support persons to assist in the exercise of legal capacity for certain types of decisions (e.g. peer support, self-advocacy support); it may include measures relating to universal design and accessibility to enable persons with disabilities to perform legal acts or conduct social transactions; it may involve advance planning (e.g. advance directive); it may constitute the development and recognition of diverse non-conventional methods of communication, including non-verbal forms and that they are made available in the languages/forms best understood by them. See CRPD Committee's General Comment no. 1, and report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58.

- establishing exceptions to the full enjoyment and exercise of legal capacity or specific right(s) for persons with disabilities; and/or
- creating disability-neutral responses that disproportionately and adversely impact the exercise of legal capacity or specific right(s) by persons with disabilities.

- ensure that consultation processes are transparent and accessible;
- ensure provision of appropriate and accessible information;
- not withhold information, condition or prevent organizations of persons with disabilities from freely expressing their opinions;
- include both registered and unregistered organizations;

including those made on the assessment of mental capacity skills.

ii Including in situations of mental distress.

iii Including plenary or partial guardianship, judicial interdiction, curatorship, conservatorship and other substitute decision-making regimes.

iv including: the right to marry, to family, to exercise parental rights, sexual and reproductive health and rights, right to vote, stand for election and hold public office, to give/withdraw informed consent in healthcare and rehabilitation services, to access justice, to enter into a contract, to own or inherit property, to control their own financial affairs including having equal access to bank loans, mortgages and other forms of financial credit, for example through:

Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned. See CRPD Committee's General Comment no. 1, para. 29.

vi See CRPD Committee's General Comment No. 1, para. 17.

vii such as legal proceedings, health care and financial transactions;

viii including non-verbal forms of communication.

ix residing in an institution, in the community, within a family, etc.

x under plenary or partial guardianship, judicial interdiction, curatorship, conservatorship or other substituted decision making regimes.

xi quality standards are applicable regardless of the type of support.

including the provision of financial and technical assistance to civil society organizations to enable the creation and implementation of various supported decision-making schemes that address the needs of diverse impairment groups and constituencies in ways that are appropriate and acceptable from their own point of view.

xiii including pilot projects on formal and informal forms of support in decision-making and peer support networks, inclusive of researchers with disabilities and organisations of persons with disabilities.

residing in an institution, in the community, within a family, etc.

xv by the type and intensity of support, age, gender and type of impairment, as well as geographic location of beneficiaries, including institutions.

xvi E.g., advance directives can include instructions on how to deal with future emotional crises and/or to appoint a person to support them in those particular circumstances, and/or on personal, patrimonial or finance matters (See CRPD Committee's General Comment no. 1, para 17; A/HRC/37/56, para 32)

Awareness raising campaigns and activities should include information on: the right to have decision-making respected at all times including in situations of distress; the right to free and informed consent, strategies for supported decision-making, safeguards against abuse; non-discrimination in legal capacity, including ensuring the provision of reasonable accommodation; the prevention and elimination of informal substitute decision-making or coercive interventions in family and community settings.

This indicator requires verifying concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them in line with article 4(3) of the CRPD and General Comment no. 7 of the CRPD Committee, including consultation meetings, technical briefings, online consultation surveys, calls for comments on draft legislation and policies, among other methods and mechanisms of participation. In this regard, States must

- ensure early and continuous involvement;
- cover related expenses of participants.

xix including through substitute decision-making regimes such as plenary or partial guardianship, interdiction, curatorship, conservatorship.

	fArticle 19 - List of illustrative indi	cators on Living independently and being included in the community		
	Living independently and being included in the community			
Attributes/ Indicators	Choice of independent living arrangements*	Support services**	Accessibility and responsiveness of mainstream services***	
Structure	19.1 Legislation enacted recognizing the right to live independently and be included in the community as an enforceable right of all persons with disabilities ensuring their individual autonomy and control over their life, regardless of impairment and required level of support. 19.2 Adoption of a comprehensive national strategy and/or plan with timeframes and measurable goals to implement this right, including the availability of a range of housing options and support services. 19.2.1 Adoption of a national strategy and/or plan to achieve deinstitutionalization of all children and adults with disabilities with benchmarks, timeframes and measurable goals. 19.2.2 Adoption of a moratorium on new admissions through forced institutionalization of persons with disabilities. 19.2.3 Adoption of a moratorium on new admissions to institutions of children with disabilities (idem 23.8). 19.3 Legal provisions protecting persons with disabilities against forced evictions on an equal basis with others, in all forms of housing tenure (ownership, formal rental agreements, informal settlements, etc.) and ensuring continuous provision of housing and necessary support. 19.4 Legal requirement to collect data on the number and proportion of persons with disabilities exercising the right to choose their living arrangements, including those leaving institutions into community life, and accessing support services for living independently. 19.5 Legal requirement to establish a marker on all spending related to the exercise by persons with disabilities of the right to choose their living arrangements and access support services for living independently. 19.6. No legal provision restricting directly or indirectly the right of the right of the vertical part of the right of the right of the vertical part of the right of the right of the vertical part of the right of the ri		19.12 Adoption of uniform national accessibility standards respected and ensured by all mainstream services, including all public administration and private facilities providing services to the public. 19.13 Adoption of a strategy or plan(s) to ensure the universal design, accessibility, cultural appropriateness, and responsiveness of mainstream services to persons with disabilities, including the provision of reasonable accommodation to persons with disabilities.	
	of persons with disabilities to choose where and with whom to live on equal basis with others. vii 19.7 Adoption of mandatory accessibility standards for housing accessible to all persons with disabilities. 19.8 Adoption of a national strategy and/or plan to ensure the availability and affordability of housing options, including accessible and adaptable units, for persons with disabilities, across all areas of the community. viii	access, availability and diversity of support allowances and services for persons with disabilities, including "person-directed/user"-led human support, is support tailored to situations of mental distress, psychosocial crisis and other intermittent or emergent needs, and the provision of assistive devices and technologies. 19.10 Availability of support measures, including home support, peer counselling and financial support or allowance for persons with disabilities and those relatives and/or others with whom the person decides to live. 19.11 Adoption of a national policy to ensure support to families of children with disabilities to prevent family separation, including the provision of appropriate and adequate social services for quality family-based alternative care options, to ensure the right of children with disabilities to a family life and inclusion in the community. 11		
Process	geographical location. 19.15 Number and proportion of all public sector staff and private actors involved in the housing policy and market trained on the rights of persons with disabilities, and on relevant aspects of this right. xiii 19.16 Number and proportion of facilities of disability-specific deprivation of liberty (such as institutions, including group homes, residences for persons with intellectual disabilities, etc.) closed down per year, disaggregated by type of institution and geographical location. xiv 19.18 Number and proportion of persons with disabilities living in in	19.17 Number of persons, including professionals, certified to provide support services in-home, residential and other community support services, including personal assistance to support living and inclusion in the community, non-coercive forms of support tailored to situations of mental distress or psychosocial crisis, and other forms of support, per 1000 persons with disabilities, disaggregated by type of certification and/or profession.	19.24 Training of staff of mainstream services on the rights of persons with disabilities, in particular on non-discrimination and the provision of reasonable accommodation, to increase responsiveness to the individual's needs. xii 19.25 Budget allocated to accessibility and provision of reasonable accommodation within mainstream services. 19.26 Proportion of mainstream service providers that fully comply	
	to facilitate transitioning from institutional care to living in the community. 19.19 Number and proportion of staff trained to support transition from institutional care to people with disabilities living independently and being included in community. 19.20 Awareness raising campaign and activities to promote the right of persons with disabilities to live independently and live in the community, targeting the general public as well as the diversity of persons with disabilities and their relatives, including dissemination of information on the range of entitlements, services and housing available.		with national accessibility standards.	

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	19.21 Budget allocated to measures aimed at ensuring the right of persons with disabilities to choose their living arrangements and access support services for living independently, and average amount spent per person as compared to amount spent per institutionalized person with disabilities. 19.22 Consultation processes undertaken to ensure active involvement of persons with disabilities, including through their organizations, in the design, implementation and monitoring of laws, regulations, policies and programmes to ensure the right to live independently and be included in the community. 19.23 Proportion of received complaints on the right of persons with disabilities to live independently and be included in the community that have been investigated and adjudicated; proportion of those found in favour of the complainant; and proportion of the latter that have been complied with by the government and/or duty bearer; each disaggregated by kind of mechanism		
Outcome	19.27 Number and proportion of adult persons with disabilities heads of household disaggregated by sex, age, disability and kind of entitlement (owner, tenant, etc), as compared to other persons. The second secon	based support services, including personal assistance, out of the total number of requests made, disaggregated by sex, age and disability and support service provided. 19.31 Number and proportion of persons with disabilities provided with assistive devices and technologies for independent living, out of the total number of requests made, disaggregated by sex, age, disability and assistive	19.35 Number of persons with disabilities using mainstream services, and proportion out of the total of service users, disaggregated by sex, age, disability, and type of service, as compared to other persons. XVIIII 19.36 Number and proportion of requests for reasonable
	19.32 Number and proportion of persons with disabilities currently residing in institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities, etc. from large scale facilities to group homes), disaggregated by sex, age, disability, and type of institution/facility. 19.33 Number and proportion of persons with disabilities who have left institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities, etc.) and entered into independent living arrangements, out of the total of persons with disabilities institutionalized, disaggregated by sex, age and disability. 19.34 Number and proportion of persons with disabilities released from institutions and provided with community based support services, including		accommodation granted to persons with disabilities in using mainstream services. 19.37 Level of satisfaction of persons with disabilities with mainstream services disaggregated by type of service, sex, age and disability.

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- * See CRPD Committee, General Comment no 5 on Article 19, para 16: "(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 not 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 set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; 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 deinstitutionalization 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".
- **"Support services" constitute a broad term that encompass different kinds of services whose purpose, design and/or outcome is to facilitate the inclusion and participation of persons with disabilities in the community, preventing isolation and segregation from others, e.g. personal assistance for daily living. Support services:
 - include services both within and outside the home:
 - may extend into the spheres of employment, education and political and cultural participation; etc.
- include supports specifically tailored to psychosocial crisis ('mental health crisis') situations which have the aim of facilitating the person's ability to continue to meet their needs in the community and to prevent isolation and segregation.
 - may vary in name, type or kind according to the cultural, economic and geographic specificities of each State.
 - must comply with a set of criteria (see below endnote ix). See also Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58.

personal assistance, to the extent requested by the person, disaggregated by sex, age and disability and support service provided.

*** The concept of "mainstream services" refers to a wide variety of services available to the community and are as well referred to by the CRPD Committee as "community services and facilities" and/or "general services". As such, they include "accessible information and communications technologies, websites, social media, cinemas, public parks, theatres and sports facilities" (general comment 5, on Article 19 of the CRPD), but also education, health, administrative services by governments, etc. In this sense, when utilizing indicators under this attribute for reporting and or monitoring, the focus should be on the existence and implementation of plans and measures across "general services" to adopt and comply with accessibility standards and the provision of reasonable accommodation when required in particular cases.

¹ The diversity of cultural approaches to human living and family life and models must not prevent persons with disabilities from exercising autonomy and control over their lives.

"Such a plan should foresee:

- availability of housing, delinked from any obligation to accept services, that meets accessibility and affordability needs of the diverse population of persons with disabilities. Housing options may include ownership, rental, co-housing, family housing and any other form of housing customary for the general population in a particular community, which meets the requirements of respecting the individual autonomy of persons with disabilities. (See indicator 19.8)

availability, without financial barriers, of support services including personal assistance to be provided in the context in which the person requests such support (at home, participating in activities, etc.), designed by the individual or freely accepted and readily adaptable to the individual's needs (See indicator 19.9)

Deinstitutionalization requires supporting individuals to explore and assert their will and preferences concerning: where and with whom to live; whether to receive support services and what types of services; and the provision of social and economic assistance designed to meet transitional needs, including support in finding employment. Social assistance and support must be designed and delivered in a culturally appropriate manner sensitive to the individual, recognizing the harm caused by institutionalization; it should offer services tailored to the individual's needs according to their will and preferences.

A plan for deinstitutionalization should explicitly include:

- The immediate cessation of detention of all individuals who are confined against their will in mental health services or other disability-specific forms of deprivation of liberty;
- Measures to provide social and economic assistance designed to meet the transitional needs of persons with disabilities who leave institutions;
- The absolute prohibition of building, developing or investing in new institutions for persons with disabilities, either by the State or by private entities;
- Prohibition of the renovation of existing institutions, with the exception of the most urgent measures necessary to safeguard residents' physical safety;
- Appropriate and adequate resource allocation to develop community based support services, with increasing reallocation of budgetary resources from institutional care to community based care.

This should include for example, resources allocated to: housing programmes benefitting persons with disabilities; the development and delivery of support services; and costs of deinstitutionalization processes.

"Mainstream services" include, among others, public administration (e.g. municipalities, civil registry, etc.), health and education, banks, etc., and "accessibility standards" should address the different dimensions of accessibility (built environment, transportation, information and communications).

VI Such a strategy or plan should consider and include:

- accessibility of the built environment, transportation, information and communications when accessing services, and includes, among others, ramps, signage in Braille, easy to read language, sign language interpretation, captioning, alternative and augmentative modes of communications, tactile communication.
- Measures to identify barriers faced by persons with diverse types of disabilities in using mainstream services in order to remove them and improve access.

E.g. restriction or denial of legal capacity contrary to Article 12 of the CRPD, laws allowing deprivation of liberty based on mental health condition or impairment, laws or regulations conditioning access to social housing upon compliance with a particular treatment, etc.

viii Measures in this regard may include:

- Direct attribution of social housing units;
- Promotion and facilitation of affordable loans for persons with disabilities to become home owners
- Tax or other exemptions to compensate private spending to ensure accessibility (e.g. renovation of entrance ways, corridors, living spaces bathrooms, etc.)

^{ix} Provision of support services, notably personal assistance services, must respect the following criteria:

Service control

- The support service must be controlled by the person with disability (e.g. by directly contracting the service from a variety of providers, or acting as an employer; custom designing their own service, instructing and directing service providers);
- Personal assistants must be recruited, trained and supervised by the individual who is granted personal assistance;
- Personal assistants should not be "shared" without the full and free consent of the individual who is granted personal assistance;
- Persons with disabilities requiring personal assistance can freely choose the degree of personal control over service delivery according to their life circumstances and preferences; and
- The control of personal assistance can be exercised through supported decision-making.

Funding allocation / allowance

- Funding allocation for hiring a personal assistant must follow personalized criteria, be based on an individual needs assessment with regard to individual life circumstances, and respect for human rights standards, as well as national legislation and regulations, for decent employment.
- Eligibility criteria must not be limited to medical criteria;
- Individualized services must not result in a reduced budget and/or higher personal payment;
- Funding is to be controlled by, and allocated to the person with disability with the purpose of paying for any assistance required;
- Programmes and entitlements to support living independently in the community must cover disability-related costs;
- Allowances and cash transfer schemes must distinguish clearly income support due to lack of income from coverage of disability related costs.

Decentralisation of service provision and transferability

- Decentralisation of service provision should not undermine the quality nor compliance with the criteria enumerated above.
- Support allowances and services should be transferable within the different regions of the State and regional organisation.

^x See Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58, para 14, also the factsheet on assistive devices and technologies.

Policies should explicitly call for ending the institutionalisation of children and prioritising investments in social services to support families and communities to prioritize family preservation; If the immediate family is unable to care for the child, alternative care within the wider family should be prioritised, then quality family-based alternative care options, including kinship and foster care within family-based settings.

xii The training should include:

- the human rights based approach to disability;
- communication with persons with disabilities, including on alternative means and modes of communication;
- the obligation to provide reasonable accommodation.

xiii This includes:

- Social housing public policy makers;
- Chambers, confederations or Associations representing real estate agents and brokers;
- Tenants associations;
- Notaries Associations.

In order to assess whether or not an institution (of any kind) has effectively been closed down, the focus should be on simultaneously verifying the use of the facilities in practice and on whether persons with disabilities who were institutionalized there have moved into the community, in order to gauge effective closure and identify "renaming" or "recycling" of institutions (e.g. a residential institution for children with disabilities being re-labelled as an aboarding school for special education).

xv This indicator requires verifying concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them in line with article 4.3 of the CRPD and general comment no. 7 of the CRPD Committee, including consultation meetings, technical briefings, online consultation surveys, calls for comments on draft legislation and policies, among other methods and mechanisms of participation. In this regard, States must

- ensure that consultation processes are transparent and accessible;
- ensure provision of appropriate and accessible information;
- not withhold information, condition or prevent organizations of persons with disabilities from freely expressing their opinions;
- include both registered and unregistered organizations;
- ensure early and continuous involvement;
- cover related expenses of participants.

xvi Given the complexity of assessing the subjective element of choice, particularly where options and resources are limited, the concept of head of household may be considered as a proxy indicator that may illustrate, to some extent, that persons with disabilities are exercising choice of living arrangements and living independently.

xvii Self reporting assessments, within disability and/or quality of life surveys or studies, may prove useful to capture the level of satisfaction of persons with disabilities with their living arrangement and level of independence, as a means to provide a proxy indication on the extent of the exercise of choice.

xviii This indicator seeks to gather information across different mainstream services (e.g. governmental administrative services, education, health, etc.) and contributes to give an overall picture of their inclusiveness and responsiveness to persons with disabilities. A result in which the proportion of users with disabilities is similar to the proportion of persons with disabilities in the total population (considering age, geographical coverage, etc.) could indicate inclusive delivery of the specific service; e.g. enrollment rate of persons with disabilities in regular education gives an indication of an inclusive education system. However, this should not been taken categorically, several other factors come into play including the particular purpose or characteristic of the service (e.g. it might be the case that persons with disabilities represent a higher proportion of users of rehabilitation services).

Article 23 - List of illustrative indicators on respect for the home and the family				
	Right to respect for the home and the family			
Attributes/ Indicators	Non-discrimination in family life	Parental rights of persons with disabilities	Right of children with disabilities to grow up in a family environment within the community	
Structure	23.1 Legislation enacted on family life which is inclusive of persons with disabilities, and which provides for the right to support or assistance for persons with disabilities and their families. 23.2 No provision in the law relating to family life which restricts directly or indirectly on the basis of disability, the right to marry on the basis of free and full consent, to found a family, to decide on the number and spacing of children (including equal access to sexual and reproductive health-care services) and the right to adopt and to be adopted.		23.3 Legislation enacted which explicitly prohibits the separation of children from their parents on the basis of the disability of the child. 23.4 Legislation enacted which ensures the right of children with disabilities without parental care to alternative care in a family setting within the community.	
	23.5 Adoption of regulations and policies to ensure equal access to sexual and reproductive health-care services and family planning services for persons with disabilities.	separation of children from their parents on the basis	23.8 Adoption of a moratorium on new admissions to institutions of children with disabilities (idem 19.2.3). 23.9 Adoption of a national policy for the deinstitutionalisation of children with disabilities, including timeframes and measurable goals. 23.10 Adoption of a national policy to ensure support to families if of children with disabilities to prevent family separation, including the provision of appropriate and adequate social services for quality family-based alternative care options, to ensure the right of children with disabilities to a family life and inclusion in the community.	
Process	23.11 Budget allocated on measures to provide support or assistance to parents with disabilities to exercise their child-rearing responsibilities. 23.12 Number and proportion of judges, notaries, health-care professionals, social workers, and related professionals trained on non-discrimination on the basis of disability, in particular concerning the right to marry, right to found a family, sexual and reproductive rights, adoption, parental rights, the obligation to provide procedural accommodations in legal proceedings, reasonable accommodation, accessible and alternative forms of communication, etc.		23.13 Budget allocated on measures to deinstitutionalize children with disabilities compared to the budget allocated to institutional care. ix 23.14 Number and proportion of staff of residential institutions for children, social workers and related professionals trained on the rights of children with disabilities to facilitate their deinstitutionalization. 23.15 Budget allocated on measures to ensure the provision of support to children with disabilities and their families, and to provide alternative care in a family setting within the community.	
	23.16 Awareness raising campaigns and activities to promote and inform persons with disabilities, their families and the general public, on the rights of persons with disabilities in family I and relationships (including equal access to sexual and reproductive health-care services), on the right of children with disabilities to live in a family setting within the community, and combat related negative attitudes, myths and stereotypes. 23.17 Consultation processes undertaken to ensure active involvement of children and adults with disabilities, including through their representative organizations, children-led initiative etc., in the design, implementation and monitoring of laws, regulations, policies and programmes related to the rights of persons with disabilities in family life and relationships, including t right of children with disabilities to live in a family setting within the community. * 23.18 Proportion of received complaints on the right to respect for home, family and relationships, alleging discrimination on the basis of disability and/or involving persons with disabilities that have been investigated and adjudicated; proportion of those found in favour of the complainant; and proportion of the latter that have been complied with by the government and/			
Outcome	their own informed decisions regarding sexual relations, contraceptive use and reproductive health care (based on SDG indicator 5.6.1) by age and disability, geographical location (idem. 6.19). 23.20 Number of persons with disabilities victims of discrimination on the basis of disability regarding family life and relationships whose rights have been restored or their violations remedied. dispersion of the production of th	3.21 Number and proportion of households with children ith at least one parent with disability. 3.22 Number of persons with disabilities accessing ainstream assistance and support services for the exercise parental responsibilities, disaggregated by sex, age and sability, type of assistance/support, and proportion they present out of persons accessing those services. 3.23 Number of persons with disabilities accessing sability specific assistance and support services for the sercise of parental responsibilities, disaggregated by sex, are and disability, type of assistance/support, and oportion they represent out of all persons with disabilities questing those services. 3.24 Level of satisfaction of persons with disabilities with apport services for the exercise of parental rights. xii	23.25 Number of children with disabilities and their families accessing assistance and support services, disaggregated by sex, age and disability of the child(ren), type of assistance/support, and proportion they represent out of all families requesting those services. 23.26 Number and proportion of children with disabilities in alternative care as compared to all children in alternative care ((in a family setting / in small group homes or other residential care facilities), disaggregated by sex, age, disability and kind of setting. (idem 7.26)	

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ⁱ This includes:

- No provision restricting rights directly or indirectly on the basis of disability, such as on the basis of decision-making skill, mental capacity, legal capacity status, etc.
- No provision restricting the right to marry on the basis of disability, including through any form of deprivation of legal capacity (e.g. guardianship), in particular to persons with intellectual disabilities and persons with psychosocial disabilities.
- No requirement conditioning the right to marry, including health related requirements, that directly or indirectly discriminates on the basis of disability. E.g. requiring judicial authorization for persons with intellectual disabilities to marry.
- No requirement of a mandatory prenuptial medical examination which applies exclusively to persons with disabilities as a pre-condition to marry, to freely choose their partner, to receive financial assistance grants related to marriage, or for any other purpose that may restrict these rights on the basis of disability.
- No restriction to parental rights on the basis of disability, including no provision allowing for the separation of children from their parents, or removal of custody from the parents, on the basis of the disability of one or both of the parents.
- No restriction imposed on adults on the basis of disability concerning guardianship, wardship, trusteeship, adoption of children or similar institutions, where these arrangements exist in national legislation.
- No provision allowing involuntary practices (including where consent is given by a third party, such as parents or guardians, in contradiction with Article 12 of the CRPD), such as forced sterilization, which violate the right of persons with disabilities, including children with disabilities, to retain their fertility and to preserve their identities.
- The reference to "alternative care in a family setting within the community" encompasses situations where the immediate family is unable to care for a child with disabilities, and requires States to undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting, in accordance with Article 23(5) of the CRPD.
- The actual or perceived disability of a parent, on its own or jointly with other considerations, should be prohibited as justification to discontinue or remove parental rights including custody rights. Determination of the best interest of the child should be based on non-discriminatory criteria.
- This should include a diverse range of non-mandatory support measures, including e.g. social protection benefits and support services which are tailored to the particular needs and circumstances of parents with disabilities (e.g. support measures for single parents with disabilities), parenting skills training programmes inclusive of persons with disabilities, parent peer support groups inclusive of parents with disabilities or those created by and for parents with disabilities, etc. All support services and related information and communications should be made accessible for all persons with disabilities, taking into account the principle of universal design.
- This moratorium includes new admissions to both large and small group homes for children. For more details on what constitutes an "institution" in the context of this indicator related to children with disabilities, see CRPD Committee, general comment no. 5 on Article 19, CRPD/C/GC/5, para. 16(c) in fine.
- vi On deinstitutionalization of adults with disabilities, see the indicators on Article 19 of the CRPD.
- vii Support measures must include the availability of early and comprehensive information, services and support to children with disabilities and their families, and be tailored to the particular needs and circumstances of the child with disability and the family, e.g. funding for parents of deaf children to learn sign language. All support services and related information and communications should be made accessible for all persons with disabilities, taking into account the principle of universal design. Information, services and support related to psychosocial disability should avoid medicalization of children's distress and ensure that the child is supported directly and confidentially to express themselves within and outside the family.
- viii Policies should explicitly call for prioritising investments in social services to support families and communities to prioritize family preservation; if the immediate family is unable to care for the child, alternative care within the wider family should be prioritised, then quality family-based alternative care options, including kinship and foster care within family-based settings. See CRPD Committee, general comment no. 5 on article 19 of the CRPD.
- ix This indicator requires the total amounts in order to compare the allocation of public budget in both directions.
- ^x This indicator requires verifying concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them in line with article 4.3 of the CRPD and general comment no. 7 of the CRPD Committee, including consultation meetings, technical briefings, online consultation surveys, calls for comments on draft legislation and policies, among other methods and mechanisms of participation. In this regard, States must
 - ensure that consultation processes are transparent and accessible;
 - ensure provision of appropriate and accessible information;
 - not withhold information, condition or prevent organizations of persons with disabilities from freely expressing their opinions;
 - include both registered and unregistered organizations;
 - ensure early and continuous involvement;

cover related expenses of participants.

- xi This indicator includes for instance:
- Persons formerly deprived of legal capacity on the basis of disability whose legal capacity is restored, restoring in turn family rights, including parental rights (e.g. regaining custody of their children)
- Persons with disabilities who have been subjected to forced sterilization, forced abortions, forced contraception, etc., and are entitled to reparation and redress.
- xii Surveys on the level of satisfaction of persons with disabilities for the exercise of parental rights may prove useful as an assessment tool that captures the view of right holders.