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Matters related to the implementation of the Convention:
round-table discussions

Living independently, being included in the community

Note by the Secretariat**

The present background paper was prepared by the Secretariat in consultation with United Nations entities, representatives of civil society and other relevant stakeholders to facilitate the round-table discussion on the theme “Living independently, being included in the community”. The Secretariat hereby transmits the note, as approved by the Bureau of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, to the Conference at its fourteenth session.

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* CRPD/CSP/2021/1.
** The aim of the present background paper is to facilitate the round-table discussion under its sub-theme. In consultation with the relevant offices of the United Nations Secretariat, the report has an eight-page limitation. The report is to be approved by the Bureau of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities before it is processed by the relevant offices for official issuance.
Background paper for round table 2, on the theme “Living independently, being included in the community”

I. Introduction

1. Living independently and being included in the community are essential to the well-being of persons with disabilities. However, many persons with disabilities experience discrimination and numerous barriers, and face challenges on a daily basis that affect their ability to enjoy these rights and freedoms. These have been exacerbated by the coronavirus disease (COVID-19) crisis.

2. In accordance with general comment No. 5 (2017) of the Committee on the Rights of Persons with Disabilities (CRPD/C/GC/5), for the purpose of the present background paper, the terms “living independently” and “independent living” are used interchangeably and refer to individuals with disabilities being provided with the necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. The phrase “being included in the community” refers to the right to be included in the community, relating to the principle of full and effective inclusion and participation in society, as enshrined in article 3 (c) of the Convention on the Rights of Persons with Disabilities, among others. It includes living a full social life and having access to all services offered to the public and to persons with disabilities. These services can relate, among other things, to housing, transport, shopping, education, employment, recreational activities, social events and all other facilities and services offered to the public, including social media.

3. Many persons with disabilities are not given the opportunity to make individual choices and are unable to exercise control over their own lives. It is often presumed that they are unable to live independently in communities of their choice. Thus, support is often either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed to be accessible. Correcting this begins with person-centred planning conducted within a framework of supported decision-making and community-delivered support services.

4. The cost of living and rights related to those arrangements have been thrown into sharp relief during the COVID-19 pandemic. As the Special Rapporteur on the rights of persons with disabilities noted in his report (A/HRC/46/27), the placement of persons with disabilities in institutions heightened their risks many times over of contracting the virus. Such congregated settings should not exist since they are a form of unjustifiable segregation or discrimination and they cannot fulfil the promise under article 19 of the Convention of living independently and being included in the community. To this basic human rights concern is now added a public health concern.

II. Relevant international normative framework

5. The right stipulated in article 19 of the Convention is connected with relevant provisions in other human rights treaties. For example, the interdependence of an individual’s personal development and the social aspect of being a part of the community is underlined in article 29 (1) of the Universal Declaration of Human Rights: “Everyone has duties to the community in which alone the free and full development of his personality is possible.” In its general comment No. 5 on persons with disabilities (1994), 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 the right to an adequate standard of living, not only including having equal access to adequate food, accessible housing
and other basic material needs, but also the availability of support services and assistive devices and technologies. The rights set out in article 19 also entail the realization of civil and political rights, including communication rights, and the right to liberty of movement and freedom to choose one’s residence (article 12 of the International Covenant on Civil and Political Rights).

6. The Convention advances a human rights-based approach to disability inclusion in many spheres of life. With the adoption of the Convention, the right to live independently and be included in the community was given legal recognition in the international normative frameworks as an essential part of the individual’s human rights, dignity, autonomy and freedom. The right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control all aspects of their lives, is recognized in article 19 of the Convention. The aim is to prevent and eliminate violence, institutionalization and segregation in domestic settings through individualized support and enabling environments for all (see A/HRC/28/37).

7. When persons with disabilities, especially those facing high barriers to their participation, are not supported with community-based services to live independently on an equal basis with others, they face risks of institutionalization, as described in general comment No. 5 (2017) of the Committee on the Rights of Persons with Disabilities, on living independently and being included in the community.

8. In other contexts in which institutionalization is uncommon, the choice in, cost or lack of services often result in families providing personal services with little external support. To provide such support, family members must often reduce working hours or drop out of the labour market. Gender inequality can be exacerbated because support is most often provided by female members of the household.

9. Persons with intellectual disabilities, psychosocial disabilities and multiple disabilities, especially those with complex communication requirements, among others, are frequently not supported to live outside institutional settings or are isolated in their own households. This is contrary to article 19, which stipulates the right to live independently and be included in the community for all persons with disabilities, regardless of their support requirements, and with access to a variety of services from which they can choose. Fulfilment of obligations under article 19 also provides conditions for the full development of the personality and capabilities of persons with disabilities, for which a full range of opportunities must be made available close to their residence and in the community. Persons with disabilities, regardless of age, identity or social, economic and cultural status, are rights holders and enjoy equal protection under article 19. Thus, all appropriate measures should be taken to ensure the full development, advancement and empowerment of persons with disabilities, in particular women and girls with disabilities.

10. Furthermore, support or need for services is too often conflated with supervision and control. Persons with psychosocial disabilities are often subjected to legalized involuntary long-term institutionalization and involuntary short-term hospitalization in mental health settings. Discriminatory deprivation of liberty reinforces negative stereotypes and lowers the status of persons with psychosocial disabilities in their communities. Social and economic measures should be taken to ensure equal and equitable access by persons with psychosocial disabilities to resources that meet basic needs and needs for personal development and advancement, along with access to support that responds to the will and preferences of the person concerned.

11. In its essence, “living independently” does not mean living alone or in isolation. Rather, it means exercising freedom of choice and control over decisions affecting one’s life with the same level of independence and interdependence within society on an equal basis with others. Consequently, article 19 of the Convention refers to “living
independently and being included in the community” as a matter of rights and freedom, in which choice, autonomy, support and inclusion are mutually reinforcing and segregation and seclusion are jointly avoided. The Committee notes that 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.  

12. The realization of the right to live independently and be included in the community is interlinked with other articles of the Convention on the Rights of Persons with Disabilities, including the preamble and articles on general principles (article 3); non-discrimination (article 5); accessibility (article 9); equal recognition before the law (article 12); liberty and security (article 14); freedom from cruel, inhuman and torturous treatment (article 15); freedom from abuse and violence (article 16); integrity (article 17); respect for the family (article 23); health (article 25); work and employment (article 27); and adequate standard of living (article 28). The Convention, in its preamble, notes that many persons with disabilities live in poverty and are subject to multiple discrimination and stresses the need to address the impact of poverty. Addressing the situation requires ensuring access to personal assistance, providing adequate social protection for persons with disabilities and prohibiting discrimination in employment on the basis of disability to ensure that persons with disabilities have access to employment and decent work on an equal basis with others.

13. The Convention underscores that the cost of social exclusion is high, as it diminishes opportunity and perpetuates dependency, and therefore interferes with individual freedoms, self-determination and dignity. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse, as well as negative stereotypes that feed into a cycle of marginalization of persons with disabilities. Therefore, policies and plans of action for social inclusion of persons with disabilities, including through the promotion of their right to independent living (article 19), are cost-effective ways to ensure the enjoyment of individuals' rights, sustainable development and a reduction in poverty for all, as well as to reduce discrimination, stereotypes and stigma.

14. Article 28 establishes that all persons with disabilities should enjoy an adequate standard of living on an equal basis with others. This entails, in particular, providing support services that facilitate independence in their daily lives, such as personal assistance. It can include financial support for income replacement (in case of poverty) and coverage of disability-related costs (whether in cash or in kind). To that end, States parties are obliged to ensure access to appropriate and affordable services and devices and other assistance for impairment-related needs, in particular for those persons with disabilities living in poverty and/or facing multiple forms of structural discrimination. It also requires that persons with disabilities have equal access to public housing programmes, through affirmative measures to remove discrimination.

1 See Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017) on living independently and being included in the community.
Inclusive education systems, accessible general and specific health services, including sexual and reproductive health care for women and girls with disabilities, the availability of habilitation and rehabilitation programmes and equal opportunities in the open labour market are other examples of interconnected rights that contribute to living independently in the community.

15. Under article 19 of the Convention, States parties have an obligation to put an end to all forms of segregation of persons with disabilities and to take effective and appropriate measures to facilitate their full enjoyment of their rights. States parties have an obligation to ensure that persons with disabilities are not compelled to live within an institution and that they have the right to choose where they want to live and with whom. More specifically, there are several key elements needed for States parties to realize a standardized support level sufficient to allow the exercise of the right to live independently and be included in the community for all persons with disabilities. These elements include ensuring the right to legal capacity and providing support to exercise it; ensuring non-discrimination in accessing accessible housing; developing action plans for independent living for persons with disabilities within the community; putting in place comprehensive deinstitutionalization strategies; monitoring and sanctioning non-compliance with legislation; developing plans and guidance on accessibility requirements for all mainstream services; taking steps towards developing and implementing personalized, non-shared, needs-based and rights-based disability-specific support services; supporting families of persons with intellectual disabilities; and collecting consistent quantitative and qualitative data on persons with disabilities, including those still living in institutions of all sizes.

16. Article 14 of the Convention, along with articles 17 and 19, provides for the prohibition on the use of involuntary treatment and admission. Governments must ensure that involuntary treatment, solitary confinement and forced treatment of persons with disabilities are immediately addressed, and that plans, policies and budgets are created towards a rights-based approach to deinstitutionalization, with a timeline, social protection and compensations, community support systems and circles of care for deinstitutionalized persons and opportunities such as housing, employment and vocational skills training. All deinstitutionalized persons must have access to their personal identity documents, registrations, birth and other educational certificates, financial inclusion and other basic necessities and formalities that will help them start a new life in the community, on an equal basis with others.

17. In connection with article 19 of the Convention, targets 10.2 of the Sustainable Development Goals (empower and promote the social, economic and political inclusion of all) and target 11.1 (ensure access for all to adequate, safe and affordable housing and services) provide crucial guidance of special importance and relevance in this context. Independent living and full inclusion in the community for persons with disabilities are also dependent on reducing poverty (Goal 1), access to decent work on an equal basis with others (Goal 8) and increased accessibility in public spaces (Goal 11). Furthermore, as women and girls with disabilities have historically faced greater social exclusion and denial of their right to live independently, all measures to ensure access to these rights and freedoms must include a gender perspective (Goal 5). In addition, achieving these goals requires a focus on unpaid family members, predominately women and girls in the household who, in many countries, by default take on unrecognized, undervalued and unsupported responsibilities in the provision of personal services for their family members with disability.

18. In addition, the New Urban Agenda, in which Member States also advocated a vision of cities and human settlements where all persons could enjoy equal rights and opportunities through the promotion of inclusive, just, safe, healthy, accessible, affordable, resilient and sustainable cities and human settlements, provides important
III. Key issues and challenges

19. Although progress has been made since the entry into force of the Convention on the Rights of Persons with Disabilities in 2008, a gap remains between the goals of the Convention and its implementation on the ground. Among others, below are some key issues and challenges:

(a) Misconception, negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available support;

(b) Denial of the legal capacity of many persons with disabilities, owing either to existing formal laws and practices or de facto substitute decision-making related to living arrangements for persons with disabilities;

(c) Regimes of legalized involuntary institutionalization, including both long-term and short-term involuntary hospitalization in mental health settings, which are contrary to articles 12 and 14 of the Convention and places people with psychosocial disabilities in an ongoing situation of legal, social and economic precarity;

(d) Lack of choice, will and preferences when offering support services;

(e) Inadequacy of social support and protection schemes and budget allocations aimed at providing personal assistance and individualized support;

(f) Lack of flexibility and adequate support that corresponds to the needs of persons with disabilities, in particular persons with intellectual disabilities;

(g) Lack of available, affordable and accessible services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;

(h) Lack of support for families of children with disabilities and failure to develop inclusive education systems, resulting in many children with disabilities without access to education, growing up in institutions, including group homes and boarding schools, and being denied education on an equal basis with others;

(i) Lack of available, affordable and accessible disability-specific services and supports within public service provision and as close to home as possible, such as habilitation, rehabilitation and assistive products;

(j) Insufficient mainstreaming of disability, including in general budget allocations;

(k) Lack of deinstitutionalization strategies and plans and continued investments in institutional care settings;

(l) Inadequate support for the participation of persons with disabilities in realizing their right to live independently and be included in the community;

(m) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within a given community in a State Party country;

(n) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of the Convention, including the participation of representative organizations of persons with disabilities;
Inadequate participation of persons with disabilities in COVID-19 response planning and recovery efforts.

Specific impacts of the COVID-19 pandemic on persons with disabilities

20. The COVID-19 pandemic created a human crisis of unprecedented scale. The disaster preparedness and resilience of all countries and communities are being tested. The outbreak and its multifaceted impacts have disproportionally affected persons with disabilities, especially women and girls with disabilities, those with pre-existing health conditions, the poor and those living in institutional settings – nursing homes, psychiatric facilities, boarding schools or prisons – many of whom are persons with intellectual disabilities or persons with psychosocial disabilities.

21. COVID-19 poses a threat to the well-being of persons with disabilities, not just to their health, but also to their independence. Many persons with disabilities rely on access to support services to live independently in their own homes and communities. The COVID-19 pandemic disrupted many routine and required services, support systems and informal networks, such as personal assistance, sign language and tactile interpretation and psychosocial support. For example, assistants and caregivers may become sick themselves, the risk of spreading illness may require them to stay at home, and information on disrupted transportation services may not be available in accessible formats. The disease itself poses special risks to those living in institutionalized settings, especially if proper infection control and physical distancing measures are not taken and access to adequate treatment is denied. Disruptions in services and routines then increase the likelihood of persons with disabilities being institutionalized and consequently exposed to greater risk of infection.

22. In accordance with the policy briefs of the Secretary-General\(^2\) and the World Health Organization,\(^3\) persons with disabilities are at greater risk of contracting COVID-19, developing more severe health conditions and dying from the disease. They may experience barriers to the implementation of basic protection measures such as hand-washing and maintaining physical distancing for several reasons: lack of accessibility of water, sanitation and hygiene facilities; a reliance on physical contact to get support; inaccessibility of public health information; or being placed in institutional settings, such as nursing homes, social care homes, psychiatric facilities, boarding schools, detention facilities or similar facilities where they are more likely to contract the virus and have higher rates of mortality. The percentage of COVID-19-related deaths in care homes – where older persons with disabilities are overrepresented – ranges from 19 per cent to 72 per cent in countries in which official data is available. Persons with disabilities are at greater risk of discrimination in accessing health care and life-saving procedures during the COVID-19 outbreak.

23. For example, as reported by the Economic and Social Commission for Western Asia,\(^4\) in facing the COVID-19 pandemic, persons with disabilities in the region are found twice as likely to find health-care services and facilities inadequate, and three times more likely to be denied health care, which puts them at risk of not receiving treatment at all. In addition, almost half of persons with disabilities cannot afford health care. Moreover, persons with disabilities are particularly disadvantaged by the socioeconomic consequences of measures to control the pandemic, in terms of


\(^{4}\) Economic and Social Commission for Western Asia, “The impact of the COVID-19 on Older Persons in the Arab Region” (2020).
employment and social protection, education and access to support and services and also in terms of violence against persons with disabilities within and beyond their homes.

24. Older persons with and without disabilities face multiple and intersecting forms of discrimination that create barriers to their equal right to autonomy, forcing their dependence on family members. Lockdown measures prevent family members and caregivers from regularly visiting and providing older persons with support and services.5

25. Family members of persons with intellectual disabilities have also been affected by the socioeconomic consequences of COVID-19 as families became the only and main care and support available for their relatives with intellectual disabilities when support services became unavailable as a result of the pandemic.

IV. The way forward: realizing the rights of persons with disabilities, including the right to live independently in their communities

26. The current COVID-19 crisis is unprecedented in its scale. This calls for an unprecedented response – an extraordinary scale-up of support and political commitment – to ensure that the rights of persons with disabilities are respected, protected and promoted and that they have choice and control over their lives on an equal basis with others in their communities. Response and recovery must also ensure that persons with disabilities can access essential services, including health care and social protection services, as well as financial support, to tide over the crisis.

27. The COVID-19 pandemic has highlighted the urgency to end all forms of segregation of persons with disabilities from their communities and to accelerate deinstitutionalization reforms. As part of COVID-19 response and recovery, as well as the continued disability-inclusive implementation of the 2030 Agenda for Sustainable Development, appropriate policy interventions need to be put in place and enhanced to create enabling conditions for persons with disabilities to live independently and be included in their communities.

28. The United Nations is also taking action by partnering with and supporting Member States to ensure the rights of persons with disabilities to live independently and be included in their communities, including in the context of COVID-19 response and recovery. The aforementioned Secretary-General’s policy brief on a disability-inclusive response to COVID-19, which received wide support from over 146 States Parties to the Convention, provided action-oriented guidance not only for immediate responses to COVID-19, but also for medium- and long-term recovery and resilience-building.

29. With accumulated lessons and experiences from the past, especially since the topic was last discussed by the Conference of States Parties to the Convention, some Member States are increasingly including and engaging persons with disabilities and their representative organizations in all development agendas and efforts. Engagement of persons with disabilities must become part and parcel of the strategies that countries are preparing for their COVID-19 recovery. If well designed, these inclusive strategies will be able to grasp the emerging opportunities to build back better from the COVID-19 crises: addressing the exclusion and discrimination faced by persons with disabilities in key areas, such as access to health, employment, social protection and community support and, thus, creating more resilient communities and

societies for all. Below are some specific measures in law and policies, as well as good practices to support persons with disabilities to live more independently within their communities:

A. **Legal and administrative measures to recognize and respect the legal capacity and to support decision-making of persons with disabilities**

30. The deprivation of legal capacity undermines the choice and control fundamental to living independently and being included in the community. Several countries have reformed, or are reforming, their legal frameworks in line with the Convention.

B. **Adequate, quality services and personalized support for independent living to be made available**

31. In situations of broken supply chains, widespread shortages of essential items and lockdowns during the COVID-19 crisis, persons with disabilities may not have the resources to obtain daily necessities, such as food, toiletries and medicines, as well as hand sanitizers, hygiene kits and personal protective equipment. Mechanisms, including home delivery options, should thus be established to ensure that persons with disabilities have an adequate and continuous supply of these requisite items. Support should be provided regardless of particular living arrangements. Without such support, there is a risk that some persons with disabilities, particularly children with severe impairments, will be forced into institutional settings.

32. Measures should be taken to reduce potential exposure to COVID-19 during the provision of support services. Such measures include ensuring access to information, including by providing practical guidance and updated advice to persons with disabilities, personal assistants, carers and informal carers on how to support persons with disabilities in a manner that is safe for everyone. Observing physical distancing disproportionately impedes access to livelihoods, independent living, health care and rehabilitation for persons with disabilities. Persons with disabilities and those supporting them should be prioritized for access to COVID-19 vaccines.

C. **Personal assistance provided to those who are in need**

33. Personal assistance is an effective means to ensure the right to live independently in the community in ways that respect the inherent dignity, individual autonomy and independence of persons with disabilities.

D. **Family-based services to support the right of children with disabilities to grow up in a family**

34. All children should be able to grow up in a family, regardless of how much support they require. Access should be ensured to a range of support services, including personal assistance, and financial support. For children unable to grow up with their biological families, access to foster care, kinship care or adoption should be made possible. Access to inclusive education is a precondition for children with disabilities to be able to access education on an equal basis with others and to live independently and be included in the community as adults.
E. Develop appropriate community-based living arrangements that give a meaningful choice over where to live

35. Persons with disabilities should be empowered to choose where to live and to receive the support they may require. This requires development of and support for a wide range of living arrangements to meet their preferences, including access to mainstream housing and to personal assistance. Support must not be equated with supervision. All persons with disabilities must have the option to choose to live in their own home, rather than in any congregate setting.

36. Support for persons with disabilities may require the provision of more than personal assistance. Some need support in education, work, shopping, leisure activities and others. Some may also need decision-making support with regards to their day-to-day life and routine management. This requires development of flexible support services schemes that are based on individual needs and respect their wills and preferences.

F. Enhance the financial independence of persons with disabilities through social security and employment promotion programmes

37. Without financial independence, autonomy and choice cannot be achieved. Therefore, equal opportunities to decent employment, sufficient income support and benefits and other relevant measures are necessary as preconditions for independent living, in particular during the current multifaceted crisis of the COVID-19 pandemic. Income support and benefits must not be made conditional on any waiver of rights, for example a requirement to undergo medical treatment or to be legally incapacitated and placed under guardianship.

38. Benefits should not put the person in a situation in which they will be disincentivized to seek employment or undertake self-employment. Many persons with disabilities lose their disability-related benefits when they have a job or when they reach a certain amount of wage income. Disability-related costs should be included in calculations for social protection programmes. In such programmes, there should be clear distinctions between “income replacement or support” (due to poverty) and “coverage of disability-related costs” (due to disability).

G. Accelerate deinstitutionalization and invest in community-based solutions

39. It is important to address the urgent need for deinstitutionalization strategies with clear timelines and concrete benchmarks. These standards have been elaborated by the Committee on the Rights of Persons with Disabilities.\(^6\)

40. Particular attention should be focused on persons with disabilities living in residential institutions of all kinds, including those that are smaller in scale and may have been developed under previous “deinstitutionalization” initiatives, and more resources should be allocated to accelerate deinstitutionalization strategies and transition to community-based solutions. For instance, in the European Structural and Investment Funds Regulations 2014–2020, the availability of funding is closely linked to deinstitutionalization through a number of ex-ante conditionalities. Investing in, developing and implementing inclusive support services at the local

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level for education and primary health care, including rehabilitation, are crucial cornerstones for achieving the Sustainable Development Goal targets for persons with disabilities. These are particularly important during times of crisis, during which austerity-driven cuts to such services are common.

41. Particular attention should also be focused on persons with disabilities and their families in situations with little or no formal support available. Resources should be allocated to support people and their families to prevent institutionalization.

V. Guiding questions for consideration

42. The following guiding questions provide a basis for the round-table discussion:

(a) What major barriers and challenges are still preventing persons with disabilities from enjoying the right to live independently and be included in communities, including in current COVID-19 responses?

(b) What measures need to be adopted to prevent persons with disabilities from being further isolated, marginalized or at risk of institutionalization during the pandemic? What measures are being and should be taken to urgently accelerate deinstitutionalization, in the light of the high infection and mortality rates in these settings during the COVID-19 pandemic?

(c) What are concrete examples that illustrate which disability-inclusive policy interventions are effective in mitigating the adverse socioeconomic impact of COVID-19 and in facilitating the independent living and community engagement of persons with disabilities? What are the reasons for their effectiveness?

(d) What urgent and immediate measures should Governments take in order to achieve the right to live independently and be included in communities, including in current COVID-19 responses?

(e) What are innovative measures, including with the use of appropriate technologies, that can be introduced or promoted to mitigate the adverse impact of COVID-19 on the lives of persons with disabilities and to facilitate their independent living in their communities?

(f) How can persons with disabilities and their representative organizations realize the right to participation in relevant COVID-19 response strategies and actions at the national and local levels?

(g) How can States achieve a fully systemic change towards person-centred planning, with supported decision-making and community-delivered support services?