Chapter 5

Assistance and support
“I don’t know what to do for my mum. She is my earthly god. My family has been so supportive and helpful. They carry or feed me when I cannot. They have paid my bills. They have cared and loved me…I don’t think [I will have children] unless when God does a miracle. I am very expensive to maintain, so how can I maintain my family?”

Irene

“In my town the programs work and the different social services talk to each other. The workers helped me get an apartment and gave me money for food when I didn’t have anything to eat. I would have been kicked out of my apartment maybe two times if the worker didn’t talk to my landlord because we were butting heads. I don’t know if I would have made it without them. Those people really care about me and are committed to me. They are like my family and respect me. With the right support like that, people can grow into the right things and that needs to be thought of more. We don’t need to be taken care of but to have someone to talk to and help us learn to solve our own problems.”

Corey

“A revolution in life – and in my head! Personal Assistance [PA] means emancipation. PA means I am able to get up in the morning and to bed at night, that I can take care of my personal hygiene etc. but PA also means freedom to participate in society. I even have got a job! Now I can decide for myself how, when and by whom I shall be assisted. I get the housework and the gardening done, in addition to my personal things, and there are still hours left for recreational activities. I can also save hours, which makes it possible for me to go away on holiday.”

Ellen

“At age 16 I was afraid to be ‘weird’. As I saw no way out I conducted some suicide attempts. This led to an involuntary admission in a mental hospital with long-term seclusion, coercive medication, fixation, even body cavity searches to prevent me from self-harm or suicide. Caregivers confined me for months and months. As a result, I felt unwelcome and useless. Their treatment was not helping me at all. I got more depressed and suicidal, and refused to cooperate. I have been raised with a strong feeling of justice, and I believed this was not good care. There was no trust between the caregivers and me, only a fierce struggle. I felt like I was on a dead end and I saw no way out. I did not care for my life anymore and expected to die.”

Jolijn
Assistance and support

For many people with disabilities, assistance and support are prerequisites for participating in society. The lack of necessary support services can make people with disabilities overly dependent on family members – and can prevent both the person with disability and the family members from becoming economically active and socially included. Throughout the world people with disabilities have significant unmet needs for support. Support services are not yet a core component of disability policies in many countries, and there are gaps in services everywhere.

No one model of support services will work in all contexts and meet all needs. A diversity of providers and models is required. But the overarching principle promoted by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (1) is that services should be provided in the community, not in segregated settings. Person-centred services are preferable, so that individuals are involved in decisions about the support they receive and have maximum control over their lives.

Many persons with disabilities need assistance and support to achieve a good quality of life and to be able to participate in social and economic life on an equal basis with others (2). A sign language interpreter, for instance, enables a Deaf person to work in a mainstream professional environment. A personal assistant helps a wheelchair user travel to meetings or work. An advocate supports a person with intellectual impairment to handle money or make choices (2). People with multiple impairments or older persons may require support to remain in their homes. These individuals are thus empowered to live in the community and participate in work and other activities, rather than be marginalized or left fully dependent on family support or social protection (3, 4).

Most assistance and support comes from family members or social networks. State supply of formal services is generally underdeveloped, not-for-profit organizations have limited coverage, and private markets rarely offer enough affordable support to meet the needs of people with disabilities (5–7). State funding of responsive formal support services is an important element of policies to enable the full participation of persons with disabilities in social and economic life. States also have an important role in setting standards, regulating, and providing services (8). Also by reducing the need for informal assistance, these services can enable family members to participate in paid or income-generating activity.
The CRPD sees support and assistance not as ends in themselves but as means to preserving dignity and enabling individual autonomy and social inclusion. Equal rights and participation are thus to be achieved, in part, through the provision of support services for people with disabilities and their families. Article 12 restores the capacity of decision-making to people with disabilities. Respecting individual wishes and preferences—an often method of supported decision-making or otherwise—is a legal imperative (see Box 5.1). Articles 19 and 28 are concerned with “the right to live independently and be included in the community” with an “adequate standard of living and social protection”. Article 21 upholds rights to freedom of expression and opinion and access to information through sign language and other forms of communication.

Evidence on the demand for and supply of support services and assistance is scarce, even in developed countries. This chapter presents evidence on the need and unmet need for support services, the barriers to formal provision, and what works in overcoming these barriers.

Understanding assistance and support

This chapter uses the phrase “assistance and support” to cover a range of interventions labelled elsewhere as “informal care”, “support services”, or “personal assistance”, but as part
of a broad category which also includes advocacy, communication support, and other non-therapeutic interventions.

Some of the more common types of assistance and support services include:

- **Community support and independent living** – assistance with self-care, household care, mobility, leisure, and community participation;
- **Residential support services** – independent housing and congregate living in group homes and institutional settings;
- **Respite services** – short-term breaks for caregivers and people with disabilities;
- **Support in education or employment** – such as a classroom assistant for a child with a disability, or personal support in the workplace;
- **Communication support** – such as sign-language interpreters;
- **Community access** – including day care centres;
- **Information and advice services** – including professional, peer support, advocacy, and supported decision-making;
- **Assistance animals** – such as dogs trained to guide people with a visual impairment.

This chapter deals mainly with assistance and support in the activities of daily life and community participation. Support services in education and employment, as well as environmental adaptations, are discussed elsewhere in the report.

**When are assistance and support required?**

The need for assistance and support can fluctuate, depending on environmental factors, the stage of life, the underlying health conditions, and the level of individual functioning.

Key factors determining the need for support services are the availability of appropriate assistive devices, the presence and willingness of family members to provide assistance, and the degree to which the environment facilitates participation of people with disabilities, including older persons. When individuals with disabilities can independently get to a bathroom, for instance, they may not require another person to help them. When they have a suitable wheelchair, they may be able to negotiate their local environment without assistance. And if mainstream services are accessible, there will be less requirement for specialized support.

The need for assistance and support changes through stages of the lifecycle. Formal support may include:

- **In childhood** – respite care, special needs assistance in education;
- **In adulthood** – advocacy services, residential support, or personal assistance in the workplace;
- **In old age** – day centres, home-help services, assisted living arrangements, nursing homes, and palliative care.

Often, problems in service provision occur between these stages – such as between childhood and adulthood (15).

**Needs and unmet needs**

Data are sparse on the needs for national formal support services. Chapter 2 discussed evidence on support services. Most of the evidence about support services and assistance in this chapter comes from developed countries. This does not imply that formal assistance and support are not equally relevant in low-income settings; it suggests instead that they are rarely provided formally or that data about them are not collected.

Population surveys in Australia, Canada, New Zealand, and the United States of America have shown that between 60% and 80% of people with disabilities generally have their needs met for assistance with everyday activities (16–19). Most of the support in these countries is from informal sources, such as families and friends. For example, a survey of 1505 non-elderly adults in the United States with disability found that:

- 70% relied on family and friends for assistance with daily activities, and only 8% used home-health aides and personal assistants;
42% reported having failed to move in or out of a bed or a chair because no one was available to help;
16% of home-care users reported problems paying for home care in the previous 12 months;
45% of participants in the study worried that caring for them would become too much of a burden on the family;
23% feared having to go into a nursing home or other type of facility.

For most countries, including developed ones, and for many disability groups, there are large gaps in meeting needs for support:

- **Community support and independent living.** In China there is a shortage of community support services for people with disabilities who need personal care and lack family support (6, 22). In New Zealand a household disability survey of 14,500 children with physical disabilities reported that 10% of families reported unmet need for household care, and 7% for funding for respite care (23).
- **Communication support.** Deaf people frequently have difficulties in recruiting and training interpreters, particularly in rural or isolated communities (24, 25) (see Box 5.2). A survey on the human rights situation of Deaf people found that 62 of the 93 countries that responded have sign language interpreting services, 43 have some kind of sign language interpreters training, and 30 countries had 20 or fewer qualified sign language interpreters, including Iraq, Madagascar, Mexico, Sudan, Thailand, and the United Republic of Tanzania (27).
- **Respite services.** In the United Kingdom a large study of family caregivers of adults with intellectual disability found that 33% had a high but unmet need for respite services and 30% a high but unmet need for home-based services (28). A 2001 United States cross-sectional survey of children with special health care needs found that of the 38,831 respondents, 3178 (8.8%) reported a need for respite care in the prior 12 months, especially among younger children, mothers with low education, low-income households, and minority race or ethnicity (29).

### Social and demographic factors affecting demand and supply

Population growth affects the supply of care. Growth in older age cohorts and their rates of disability influence both supply and demand, and changes in family structure impact on the availability and willingness to provide care:

- *The ageing of consumers and ageing of family members who provide support point to a greatly increased demand for support services.* The number of people aged 60 years or over worldwide has roughly tripled – from 205 million in 1950 to 606 million in 2000 – and is projected to triple again by 2050 (30). The likelihood of acquiring a health condition increases as people age – something relevant to prospective users of support services and to family members who provide support.
- *Despite high proportions of young people in many countries – for example in Kenya 50% of the population is under 15 years of age (31) – there has been a decrease in the number of children per family (32).* Over 1980–2001 fertility rates declined in developed countries (from 1.5 to 1.2) and in developing countries (from 3.6 to 2.6). Even though infant and child mortality rates have been steadily falling in most countries, the counteracting impact of falling fertility rates is greater, with the net effect that smaller family sizes are projected (33), indicating less family care.
- *In most countries there has been an increase in geographical mobility.* With young people moving more readily from rural areas to urban centres or abroad, and with changing attitudes, shared living arrangements within families are becoming less common (33).
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It is uncertain whether informal care and existing provisions for supporting older people with a disability will cope with these demographic shifts (34). Modelling from Australia suggests that fears about future lack of caregivers may be misplaced (35).

Consequences for caregivers of unmet need for formal support services

Informal care can be an efficient and cost-effective way of supporting people with disabilities. But exclusive reliance on informal support can have adverse consequences for caregivers.

- Stress. The demands of caring often result in stress for families, particularly for women, who tend to be responsible for domestic labour, with care for family members with disability representing a significant share (36). In older age, men may also care for spouses (37). Factors contributing to stress – and possibly affecting the caregiver’s personal health – include increased time spent on care for the person with a disability, increased housework, disruptions to sleep, and the emotional impact of care (38). Caregivers also report isolation and loneliness (39).

Box 5.2. Signs of progress with community-based rehabilitation

The Ugandan government piloted a community-based rehabilitation (CBR) programme in Tororo district of Eastern Uganda in the 1990s, with support from partners, notably the Norwegian Association of the Disabled. During the initial phases Deaf people realized that they were missing out on rehabilitation services. They responded through their national umbrella organization – Uganda National Association of the Deaf (UNAD) – alerting the CBR managers and other development partners to the fact that Deaf people were being excluded because the CBR workers could not use sign language, and so could not communicate with them, and therefore could not help them to access services, information, and support.

Uganda Sign Language (USL), developed informally by UNAD in the 1970s, came to be formally recognized and approved by the Ugandan government in 1995. UNAD devised a pilot project for teaching CBR workers sign language in Tororo in 2003. The main objective was to enable Deaf people’s inclusion and participation in communities and realize their full physical and mental potential. Twelve Deaf volunteers run USL training for the CBR workers, the Deaf people and their families. So far, more than 45 CBR workers have been taught sign language: although only about 10 are fluent, the rest have a basic USL, which allows them to greet Deaf people and to provide the key information about education and employment and health among other things.

Although the project has been largely successful, some major problems encountered include the high expectations from target groups, the inadequate funds to expand to a wider area, the persistence of negative attitudes, and the high illiteracy and poverty among Deaf people and their families. These obstacles have been tackled through sensitization and awareness campaigns, intensive fundraising activities, and collaboration with the government to mainstream Deaf people’s issues in their programmes and budgets.

The story of Okongo Joseph, a Deaf beneficiary, gives an idea of how such an initiative can change lives, by enabling the CBR programmes to offer services that include the Deaf community. Okongo lives in a remote location, was born deaf, and never went to school, but has now learned sign language from UNAD volunteers who visited him at his home. Okongo writes:

“I would like to send my sincere vote of thanks to UNAD for the development you have brought to me as a Deaf person and to my family members at large. I have achieved a lot since this programme started. I really thank UNAD for the sign language programme they have taught me, my family and my new friends who work in CBR. I am now not a primitive person like before. The goat I was given is in good condition. I request for more from you. I wish you good luck.”

Source (26).
Fewer opportunities for employment. Where employment would otherwise be an option, caring for a family member with a disability is likely to result in lost economic opportunities, as caregivers either reduce their paid work or refrain from seeking it (40). An analysis of the General Household Survey in the United Kingdom found that informal care reduced the probability of working by 13% for men and 27% for women (41). In the United States members of families of children with developmental disabilities work fewer hours than members in other families, are more likely to have left their employment, have more severe financial problems, and are less likely to take on a new job (42, 43).

Excessive demands on children. When adults acquire a disability, children are often asked to help (44). Male children may be expected to enter the workforce to compensate for a parent who is no longer working. Female children may be expected to contribute to domestic tasks or to help support the parent with a disability. These increased demands on children may impair their education, and their health (45). In Bosnia and Herzegovina children aged 11–15 years whose parents were experiencing health problems or a disability were 14% more likely than other children in that age group to drop out of school (46). There are many examples, mainly from Africa, of children having to drop out of school because of a parent developing AIDS. In Uganda, among children aged 15–19 years whose parents had died of AIDS, only 29% continued their schooling undisrupted, 25% lost school time, and 45% dropped out of school (47).

Greater difficulties as family members age. As parents or other family members contributing to care grow older and become frail or die, it can be difficult for the remaining family to continue providing care. The increased life expectancy of children with intellectual disabilities, cerebral palsy, or multiple disabilities suggests that parents may eventually be unable to continue providing care for their disabled family member. This is often a hidden unmet need, as families may not have sought formal support when the disabled individual was younger, and may find it hard to seek help later in life. The needs of such families have not been adequately addressed in most countries (48), including such high-income countries as Australia (49) and the United States (50).

Policy responses to the support needs of informal caregivers can sometimes compete with the demands of people with disabilities for support for independent living and participation (51). The needs and rights of the informal caregiver should be separated from the needs and rights of the disabled person. A balance must be found, so that each person has independence, dignity, and quality of life. Caring, despite its demands, has many positive aspects that need to be brought out (52). People with disabilities who do not have families able to provide the necessary support and assistance should be a priority in formal support services.

Provision of assistance and support

Assistance and support are complex, because they are provided by different suppliers, funded in different ways, and delivered in different locations. In supply, the main divide is between informal care, provided by families and friends, and formal services, provided by government, non-profit organizations, and the for-profit sector. The cost of formal support can be met through state funding, raised through general taxation, through social insurance contributions by those covered by the scheme, through charitable or voluntary sector funding, through out-of-pocket payment to private service providers, or through a mixture of these methods. The services can be provided within a family setting or single occupancy, or congregate living in group homes or institutional settings.

While formal organized support services and programmes for people with disabilities
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are common in high-income countries, they are a fairly new concept in many low-income and middle-income countries. But even in countries with well-developed systems of support, informal care and support from families and friends predominates, being indispensable and cost-efficient. In all countries family support is essential (53). Across high-income countries families meet around 80% of the support needs of older people (52). In the United States more than 75% of people with disabilities receive assistance from unpaid informal caregivers (54). Among adults with developmental disabilities more than 75% live at home with family caregivers, and more than 25% of these caregivers are 60 years or older, with another 35% aged between 41 and 59 years. Fewer than 11% of people with developmental disabilities were living in supervised residential settings in 2006 (55).

Limited data are available on the economic value of informal care, overwhelmingly performed by women. In 2005–2006 the estimated value of all unpaid care in Australia was A$ 41.4 billion, the major part of all “welfare services resources”, which amounted to around A$ 72.6 billion (56). A Canadian study found that private expenditure, largely related to time costs for provision of assistance, accounted for 85% of total home-care costs, which escalated as activity limitations increased (57).

Government-led service delivery was traditionally focused on institutional care. Governments have also provided day services such as home care and day centres for people living in the community. With the recent trend towards “contracting out” services, governments, particularly local ones, are shifting from being direct service providers to commissioning, retaining funding and regulatory functions such as assessment procedures, standard setting, contracting, monitoring, and evaluation.

Nongovernmental organizations – also known as private not-for-profit, voluntary, or civil society organizations – have often appeared where governments have failed to provide for specific needs. Their advantages can include their potential for innovation, specialization, and responsiveness. NGOs often provide community-based and user-driven programmes to promote participation by people with disabilities in their communities (58, 59). For example, in South Africa the Disabled Children’s Action Group was set up by parents of children with disabilities, predominantly from the black and coloured communities, in 1993. The aim of this low-cost, mutual support group is to promote inclusion and equal opportunities, particularly in education. It has 311 support centres, mostly in poorer areas, with 15 000 parent members and 10 000 children and young people actively involved. Its work has been supported by grants from international NGOs as well as national charities (60).

NGOs can partner with governments to deliver services for people with disabilities (61). They also frequently act as vehicles for testing new types of service provision and for evaluating the outcomes. But many are small, with limited reach, so their good practices cannot always be disseminated and replicated more widely. Disadvantages may arise because of their fragile financial base and because they may have different priorities to government.

Private for-profit suppliers of residential and community support services exist in most societies, and their services are either contracted by government, or paid directly by the client. They are often concentrated in particular areas of the care market, such as care for the elderly and home care. Where people with disabilities can afford to do so, they or their families may employ people to support them in activities of daily living.

In practice, people with disabilities receive a range of services from different providers. For example in Australia the Commonwealth–State/Territory Disability Agreement sets the national framework to fund, monitor, and support services for 200 000 people with a disability. Community access and respite services had a high proportion of people using nongovernment services. Employment services for people with disabilities were accessed almost exclusively through NGOs. Support services in
the community were accessed mainly through government agencies (56).

**Barriers to assistance and support**

**Lack of funding**

Social safety net programmes in developing countries typically amount to between 1% and 2% of gross domestic product, and to about twice that in developed countries, although rates are variable (62). Upper middle-income and high-income countries often provide a combination of cash programmes and a variety of social welfare services. In contrast, in many developing countries, a significant share of safety net resources is often allocated to cash programmes and a variety of social welfare services. In low-income settings, social welfare services are often the only safety net, but the spending is low and programmes are fragmented and of a very small scale, reaching only a fraction of the needy population.

The lack of effective financing for support – or its distribution within a country – is a major obstacle to sustainable services. For example, in India, in 2005–06, the spending on the welfare of people with disabilities – which focused on support to national disability institutions, nongovernment organizations providing services and spending on assistive devices – represented 0.05% of Ministry of Social Justice and Welfare allocations (5).

In countries that lack social protection schemes, funding assistance and support can be problematic. Even in high-income countries, funding long-term care for older people is proving difficult (21, 63). An Australian study found that 61% of caregivers of people with profound or severe disabilities lacked any main source of assistance (64). In many middle-income and low-income countries governments cannot provide adequate services and commercial service providers are either not available or not affordable for most households (65).

Governments often do not support the voluntary sector to develop innovative services able to meet the needs of families and individuals with disabilities. In Beijing, China, in addition to existing government welfare institutions, a small number of nongovernmental housing support agencies have been set up for children and young people with a disability. A study of four of them showed that the main service was skills training (6). The government does not support these organizations financially, though the local government subsidizes the fee for a small number of the most disadvantaged children or orphans (66). Instead, the services rely on fees paid by families and donations, including international assistance. As a result, the services are likely to be less affordable to users and their quality and staffing arrangements will probably suffer (67). In India NGOs and independent living organizations are often successful in innovating and creating empowering services, but they can rarely scale them up to wider coverage (5).

**Lack of adequate human resources**

Personal support workers – also known as direct care workers or home aides – play a vital role in community-based service systems, but there is a shortage of such workers in many countries (68–70). As the proportion of older people in a country increases, the demand for personal support workers will grow. In the United States, for example, the demand for personal support workers far exceeds their availability. But their numbers are growing, and it has been estimated that the number of home health aides will increase by 56% between 2004 and 2014 and the number of personal and home care aides by 41% (71). A study in the United Kingdom estimated that 76 000 individuals were already working as personal assistants funded through direct payments schemes (72).
Many personal support workers are poorly paid and have inadequate training (70, 73). A United States study found that 80% of social care workers had no formal qualifications or training (74). Many workers may be working in social care temporarily, rather than as a career. A study in the United Kingdom found that only 42% of personal assistants had qualifications in social care (72). Combined with their high turnover, the result can be substandard care and a lack of a stable relationship with the service user.

Many support workers are economic migrants, lacking skills and a career ladder. They are vulnerable to exploitation, particularly given their precarious immigration status. The high demand for support workers in more affluent countries has led to an inflow of people, largely women, from neighbouring poorer countries – for instance, from the Plurinational State of Bolivia to Argentina or from the Philippines to Singapore. The knock-on effect of this migration – described as a “global care chain” (75) – is that in their home countries, other relatives have to step in to act as caregivers.

Inappropriate policies and institutional frameworks

From the 18th and 19th century onwards, the main framework for formal services was to provide support by placing persons with disabilities in institutions. Until the 1960s people with intellectual impairments, mental health conditions, and physical and sensory impairments usually lived in segregated residential institutions in developed countries (76–78). In developing countries institutions along similar lines were sometimes initiated by international NGOs, but the sector remained minimal compared with high-income countries (79–81).

Although it was once thought humane to meet the needs of people with disabilities in asylums, colonies, or residential institutions, these services have been widely criticized (82, 83). Lack of autonomy, segregation from the wider community, and even human rights abuses are widely reported (see Box 5.3).

People with disabilities worldwide have been demanding community-based services that offer greater freedom and participation. They have also promoted supportive relationships that allow them to exercise more control over their lives and to live in the community (85). The CRPD promotes policies and institutional frameworks that enable community living and social inclusion for people with disabilities.

Inadequate and unresponsive services

In some countries support services are available only to people living in sheltered housing projects or institutions and not to those living independently. Institution-based services have had limited success in promoting independence and social relationships (86). Where community services do exist, people with disabilities have lacked choice and control over when they receive support in their homes. Disabled people often see relationships with professionals, seldom disabled themselves, as unequal and patronizing (87). Such relationships have also led to an unwanted dependency (88).

Some recent reviews reveal that while community living shows significant improvements over institutional living, people with disabilities are still far from achieving a lifestyle comparable to that of people not disabled (2). For many people with intellectual impairments and mental health conditions, the main community service is attendance at a day centre, but a review of a range of studies failed to find good evidence of benefits (89). The community service often fails to provide an entry to employment, produce greater satisfaction (85), or deliver meaningful adult activities (90).

Poor service coordination

Where services are delivered by different suppliers – at local or national level, or from health, education, and housing, or from state, voluntary, and private suppliers – coordination has often been inadequate. Existing
services and support schemes may be operated, in any given place, by a range of public or private providers. In India different NGOs or agencies serve different impairment groups, but the lack of coordination between them undermines their effectiveness (5). Multiple assessments and different eligibility criteria make life more difficult for people with disabilities and their families, particularly in the transition between services for young people and those for adults (91). Lack of knowledge about a disability can be a barrier to referrals for effective support services and care coordination (15), as can a lack of communication.
between different health and social care agencies.

**Awareness, attitudes, and abuse**

People with disabilities and their families often lack information about the services available, are disempowered, or are unable or unwilling to express their needs. A Chinese study of caregivers of stroke survivors found a need for information about recovery and stroke prevention, and for training in moving and handling (92). A study of family care for children with intellectual disabilities in Pakistan revealed stigma in the community and lack of knowledge about effective interventions, causing distress for caregivers (93). A Belgian study of family caregivers of people with dementia found that lack of awareness of services was a major barrier to service use (94).

Empowerment through disability rights organizations, community-based rehabilitation organizations, self-advocacy groups, or other collective networks can enable individuals with disabilities to identify their needs and lobby for service improvement (95). Most countries that have developed support services have strong organizations of persons with disabilities and their families lobbying governments to reform policies on service delivery and to increase or at least maintain the resources allocated. In the United Kingdom support from a disabled people’s organization is an important influence on people with disabilities signing up for direct payment schemes (96).

As explored in Chapter 1, negative attitudes are a cross-cutting issue in the lives of people with disabilities. Negative attitudes towards disability may have particular implications for the quality of assistance and support. Families hide or infantilize children with disabilities, and caregivers might abuse or disrespect the people they work with.

Negative attitudes and discrimination also undermine the possibility for people with disabilities to make friends, express their sexuality, and achieve the family life that non-disabled people take for granted (97).

People who need support services are usually more vulnerable than those who do not. People with mental health conditions and intellectual impairments are sometimes subject to arbitrary detention in long-stay institutions with no right of appeal, in contravention of the CRPD (98, 99). Vulnerability – both in institutions and in community settings – can range from the risk of isolation, boredom, and lack of stimulation, to the risk of physical and sexual abuse. Evidence suggests that people with disabilities are at higher risk of abuse, for various reasons, including dependence on a large number of caregivers and barriers to communication (100). Safeguards to protect people in both formal and informal support services are therefore particularly important (101).

**Addressing the barriers to assistance and support**

**Achieving successful deinstitutionalization**

A catalyst for the move from institutions to independent and community living was the adoption in 1993 of the United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, which promoted equal rights and opportunities for people with disabilities (102). Since these rules were issued, there has been a marked shift in many high-income countries and countries in transition, from large residential institutions and nursing homes to smaller settings within the community, along with the growth of the independent living movement (103–105). Countries such as Norway and Sweden have eliminated all institutional placements. Elsewhere – including Australia, Belgium, Germany, Greece, the Netherlands, and Spain – institutional care exists alongside alternative community living arrangements (106). In a major transformation in eastern Europe, countries no longer rely predominantly
Alternative care services have been progressively developed – including day care, foster care, and home support for people with disabilities. Romania closed 70% of its institutions for children between 2001 and 2007, but for adults the process has been slower. Alongside deinstitutionalization, there has also been decentralization from central to local government and an expansion and diversification of social services and service providers.

Plans for closing an institution and moving residents to community settings should be started early. Adequate resources need to be available for the new support infrastructure before attempts are made to alter the balance of care. Deinstitutionalization takes time, especially if individuals are to prepare for their new lives in the community and be involved in decisions about their accommodation and support services. Some “double funding” of institutional and community systems will therefore be needed during the transition, which may take several years.

The lesson from deinstitutionalization in various countries is that it requires a range of institutional assistance and support services, including:
- health care
- crisis response systems
- housing assistance
- income support
- support for social networks of people living in the community.

Unless the agencies responsible for these services work together, there is a danger that individuals will not obtain adequate support at crucial times in their lives. People with mental health conditions may need support and service coordination to reduce vulnerability to homelessness. Some countries, including Denmark and Sweden, have excellent coordination between health care, social service providers, and the housing sector, allowing people with disabilities to find living arrangements that suit their needs.

**Outcomes of deinstitutionalization**

Improvements in the quality of life and personal functioning have been found in several studies of people who move out of institutions into community settings. A study in the United Kingdom of people with intellectual impairments 12 years after leaving residential institutions showed that both quality of life and care were better in the community than in hospitals. Small-scale living arrangements offer people with intellectual impairments more friends, more access to mainstream facilities, and more chances to acquire skills – they also result in greater satisfaction. Evidence from a Chinese study shows that residents with intellectual impairments in small residential homes experienced better outcomes at lower cost than persons living in medium-size group homes or institutions.

In some countries, deinstitutionalization programmes have converted institutions into alternative facilities, such as:
- vocational training and resource centres;
- rehabilitation centres providing specialist secondary and tertiary services;
- smaller home units where people with complex impairments can live semi-independently with some support;
- respite facilities where people with disabilities can come for short breaks and training;
- clubs or similar centres for people with mental health issues to achieve peer support and respite;
- emergency sheltered accommodation, not only for people with disabilities but for all who may be vulnerable to abuse or exploitation.

**Comparison of costs**

The mix of evidence on the relative costs and effectiveness of institutional and community services shows that community services, if well planned and resourced, have better outcomes but may not be cheaper.

In the United States the cost of public institutions for people with intellectual disabilities is considerably higher than that of community-based services. However a review of
evidence from 28 European countries found slightly higher costs for community-based services (110), but the study also found that the quality of life was generally better for people living outside institutions, particularly those who made the move from an institutional to a community setting. If well planned and adequately resourced, community-based services were much more cost-effective than institutional care. A personal assistance service evaluated by the Serbian Center for Independent Living found that the scheme was more cost-effective than institutional care (116).

The European review also revealed a link between cost and quality, with lower cost institutional systems tending to offer lower quality care. The conclusion: community systems of independent and supported living – when effectively set up and managed, and when well planned to prepare services and individuals for the major change in support arrangements – delivered better overall outcomes than institutions (110).

In the United Kingdom research which found that user-controlled personal assistance schemes were cheaper than government-provided home care contributed to the adoption of a system of direct payments. But recent evidence is more cautious (117). Further research is needed to know whether paid personal assistance, which may substitute for informal care, increases costs to governments more than alternative arrangements (118–121). User-controlled arrangements have the potential to promote individual independence and to improve quality of life, but they are unlikely to produce major savings.

Creating a framework for commissioning effective support services

Governments may decide to provide a range of support services for all those in need – or they may target people who cannot afford to pay out of their own resources. Mobilizing financial resources will in both cases involve some pooling of funds.

A “pooled” system of revenue generation to finance support systems can include various forms of prepayment, the most common being through national, regional or local taxation, social insurance (through employers), and private voluntary insurance. Each may require some financial contributions by people who use services or by their families (“user charges” or “co-payments”). Mechanisms where people pay for all services out of their own resources are the least equitable (122).

Many developed countries have support services covering all those who need them (21). In other countries access to public funding for support services depends on a means test, as in the United Kingdom, where about half of all spending on social support comes from private sources (123). Other strategies to contain government spending on support services in countries with developed care systems include:

- charges to users
- restrictions on eligibility
- case management to limit the use of services
- budget-limited programmes (63).

In countries in transition that have invested widely in residential care, reallocating resources can help build community support services. In low-income and middle-income countries, for example in Yemen, there have been good examples of social funds financing support services (124).

Funding services

There are many ways to pay providers, with the main government mechanisms including:

- retrospective fee-for-service payments;
- direct budgetary allocations to decentralized providers;
- performance-based contracting;
- consumer-directed services through devolution of budgets to people with disabilities or their families.

Each method has its incentives and limitations, and each therefore has the potential to
influence how cost-effective and equitable the support system is. The success of a support system depends on the mix, volume, and deployment of staff and other resource inputs and the services they deliver. In turn, these depend on how funds are made available through the various commissioning arrangements. Devolved or direct payments to people with disabilities offer a relatively new commissioning option (125).

- In Sweden the Personal Assistance Reform Act of 1994 ensured that individuals with extensive disabilities would be entitled to cash payments from the national social insurance fund to pay for assistance. The weekly number of assistance hours is determined on the basis of need. About 70% of users buy services from local governments, and 15% have organized themselves into user cooperatives that provide services. The remainder purchase services from private companies or directly employ assistants (126). More than 15 000 individuals in Sweden use state aid to purchase services to meet their care needs (127).

- In the Netherlands the Persoonsgebonden-budget is a similar direct payment system. The most common service purchased is personal assistance – from an existing informal care provider or a nonprofessional private service provider. Introduced in 2003, when 50 000 people used the new style Persoongebondenbudget, 120 000 people were taking advantage of the scheme by 2010, when it was temporarily halted. The benefits include lower administrative costs and greater individualization of services. Evaluations have found high levels of satisfaction, better quality of life, and greater independence (128).

- In South Africa the Social Assistance Act of 2004 established a direct payment known as “grant in aid”. Individuals who already receive old age, disability, or war veterans’ benefits qualify for this additional money if they require full-time care. But the small monthly allowance is insufficient to pay for support. The scheme is currently being reviewed by the Department of Social Development (129).

Because support and assistance services have been provided almost entirely by families, formal support schemes could increase demand and substitute for informal care (121). Regulatory mechanisms, including eligibility criteria and sound and fair assessment procedures, are necessary to ensure the most equitable and cost-effective use of resources, and to allow delivery services to grow gradually.

**Assessing individual needs**

Assessment is vital to meet the needs of people with disabilities. In high-income countries assessment is a general process of deciding which categories of people can be granted entitlement, followed by evaluating individual need. It is generally carried out by formal systems for disability determination. In New Zealand, for instance, once eligibility for support services is established, access depends on (130):

- **A needs assessment.** This identifies and ranks the care and support needs of a person, without taking into account possible funding and services;

- **Service coordination or planning.** This identifies the most appropriate services and support options to meet the assessed needs, within the available funding;

- **Provision of services.** This is generally a support package of services for the person with disability, as well as for the family, where appropriate.

Assessment, historically, was based on eligibility according to medical criteria (124). The focus now is more on support needs to improve functioning, as reflected in the *International Classification of Functioning, Disability and Health* (ICF) (131). Colombia, Cuba, Mexico, and Nicaragua have recently introduced ICF-based disability assessment systems.

In many countries assessment has been separated from the delivery of services, to remove a
conflict of interests. In the Netherlands, while independent assessment agencies feel that this makes the process more transparent and objective, care providers find it less accessible and efficient (132).

In the United Kingdom assessment has shifted from being service-led (fitting the individual to the available service) to needs-based (with services appropriate to meet the need), and then to a focus on outcome (with personalized social care through enhanced choice). Self-assessment is an important part of this process. It is not always easy for service users to articulate their needs, so supported decision making may be indicated (47).

**Regulating providers**

The state has an important role in regulating, setting standards, inspecting, monitoring, and evaluating.

In the United Kingdom the Comprehensive Area Assessment evaluates the success of local authorities in implementing government policy, managing public resources, and responding to the needs of their communities. Social care providers, whether public, private, or voluntary, must register with the Care Quality Commission and face regular assessment and inspections. Social care providers are judged by seven criteria:

- improving health and well-being
- improving the quality of life
- making a positive contribution
- choice and control
- freedom from discrimination
- economic well-being
- personal dignity.

In countries where NGOs, assisted by foreign aid and local philanthropy, have been the main providers of support services, stable public regulatory frameworks and funding are needed to sustain and build on the services. Regulatory frameworks should cover:

- an assessment system
- allocation of resources (108).

In establishing regulatory frameworks, in whatever setting, people with disabilities and their families should be included, and service users should help in evaluating services (133). Service outcomes can improve when providers are accountable to consumers (8).

**Supporting public-private-voluntary services**

A variety of suppliers from different sectors (public, private, voluntary) provide support services.

In high-income countries, assistance and support services were set up mostly by charities and self-help groups, with later support from the state. This approach is still in use:

- In the past decade NGOs working on disability have been set up in the Balkan countries. Many are delivering services, often initially in pilots, with the support of state funding, such as the Serbian Social Innovation Fund (134). An example is the pilot project for interpreting in Novi Pazar, Serbia, run by the Association of Deaf and Hard of Hearing People.
- In India the National Trust Act – created as the result of a campaign for the rights of people with disabilities – has produced collaboration among a range of NGOs. The Act gives individuals with autism, cerebral palsy, intellectual impairment, or multiple impairments, as well as their families, access to government services to enable people with disabilities to live as independently as possible within their communities. It also encourages NGOs to collaborate, giving support to families who need it, and to facilitate the appointment of a legal guardian (135). Mechanisms under the Act offer training in personal assistance, to support people with a range of disabilities in the community.

Some countries have gone beyond simply supporting NGO services, by tendering services...
formerly provided by the state to the private not-for-profit sector. In Ireland, with funding from the government, NGOs provide nearly all services for people with intellectual disabilities (136). The main aims have been to provide access to specialist and complementary support services – and for the tendering to raise quality and drive down prices. This model, widely used in high-income countries, is being adopted in transition and middle-income countries. Governments retain the regulatory role of licensing suppliers and monitoring standards. But as countries shift to contracting, the processes for contracting and monitoring should be effective (108), to avoid neglect of clients or other abuses (137).

Where NGOs and disabled people’s organizations develop a role as service providers in a mixed economy of care, this can lead to tensions with their client base if they have to cut costs to remain competitive, or if they become more responsive to their funders than those they work with, or if advocacy roles are neglected in favour of service provision (138, 139).

Many countries have seen an expansion of private provision in mental health, following a fall in public provision (140), but a systematic review in 2003 found that not-for-profit providers had better performances in access, quality, and cost-efficiency than for-profit mental health inpatient services (141).

Although systems for public-private partnership are well developed in high-income countries, the situation is quite different in low-income and middle-income countries. Support services are fairly recent, and there generally is little support from the state for NGOs and for-profit organizations.

**Coordinating flexible service provision**

People with disabilities have needs for assistance and support that are not neatly packaged into what a single provider can offer. Informal assistance and support are most effective when underpinned by a range of formal systems and services, whether public or private.

Formal assistance and support must be coordinated with health care, rehabilitation, and housing. For example, a range of residential support services – independent housing and congregate living in group homes and institutional settings – should be offered alongside other support services, with the type and level based on assessed need (142). Research shows that a comprehensive package of housing adaptations and assistive technology for older people would be cost-effective because of reductions in need for formal care (143).

Several high-income countries have moved from providing generic services to a more individualized and flexible system of service provision. This calls for a high level of interagency coordination to ensure effective and continual delivery of support.

In the United States the Illinois Home Based Support Services Program, a successful direct payment scheme, supports people with disabilities and their families to decide which services to buy, including respite care, personal assistance, home modifications, recreational and employment services, therapies, and transportation. Families that used this service were less likely to place family members in institutional care (144). Efficiencies resulted because families tended to not spend all the available funds, and home-based care costs were lower than those of institutionalization (144).

In a similar vein, several countries – including Australia, Canada, and several European countries – have started to look at individualized models of funding. In this approach, public funding from different sources is allocated according to an assessment of need. The combined personal budget is then placed under the control of the individual to buy services, often within certain constraints, ranging from assistive devices and therapy to personal assistance (145–147). Increasing the power of consumers, this can make services more accountable. In consumer-directed services the professionals are available when needed, but are not the dominant
partner. Appropriate legal frameworks and infrastructure can help develop personal assistance schemes, not just for people with physical impairments but also people with intellectual impairments and mental health issues.

Consumer organizations also deliver community-based responses for mental health.
- In Zambia the Mental Health Users Network provides a forum for users of mental health services to support each other and exchange ideas and information (148).
- In the United States MindFreedom has “landing zones” for communities to provide support and housing to people so that they can avoid hospitalization or institutionalization (99).

Consumer-directed services are often less costly and just as safe as professional-directed services (149–151). Consumer-directed services probably substitute for informal care and can thus raise overall government costs (118, 119). The choice offered by such quasi-markets depends on supply, which may be lacking, especially in rural areas (152).

Consumer-directed models may not always improve efficiency and quality. Service users may find the choice and bureaucracy overwhelming. Full flexibility through direct payments and personal assistance involves responsibilities as an employer – with all the associated administrative duties, such as accounting and completing tax returns, that may be unwelcome to individuals. Some of these tasks can be undertaken by user cooperatives or agencies.

In practice, and depending on needs and preferences, people with disabilities may opt for varying levels of choice and control. In the United Kingdom, despite the growth of personal assistance schemes, the majority of people with disabilities still do not opt for direct payments (153, 154). So a range of models is needed, and further research should determine which models of personal assistance are most effective and efficient (118–121).

Support for informal caregivers
Informal care will continue to be important for people with disabilities (155). Apart from meeting assistance and support needs, it may well also be cost-effective to provide support to family members and others providing informal care, as suggested by the Illinois Home Based Support Services Program.
- Respite services – either in the home or outside the home – providing short-term breaks from caring (156). These have been developed in high-income countries and countries in transition, but unmet needs for respite are reported (157, 158).
- Direct or indirect financial support. Countries in transition, including the Republic of Moldova and Serbia, and parts of South America, where pensions have been provided for otherwise unpaid caregivers, and developing countries, such as South Africa, provide some cash benefit for caregivers in families with people with disabilities (62, 159).
- Psychosocial support services to improve family well-being.
- Paid sick leave and other support from employers to facilitate family caring.

Families can benefit from opportunities for autonomy and support services. Early family support programmes within the developmental disabilities system emerged in the 1960s in the Nordic countries and Australia (160) and in the late 1970s and early 1980s in the United States. Families in consumer-directed programmes are more satisfied with services, and have fewer unmet needs and fewer out-of-pocket expenses for disability services than those in other types of programme (161, 162).

Families may also need training in working with caregivers, roles, boundary setting, and empowering their relative with disability. They may also need information about available services. But a Japanese study found that providing information was not effective in reducing the burden on caregivers, whereas social communication did help (163).

User involvement
User involvement has become a criterion for judging the quality of service delivery. The
European Quality in Social Services initiative includes effective partnerships and participation among the principles governing its quality certification – a process complementary to national quality certification. Users can be involved in service delivery in different ways, including (108, 138, 139):

- in complaints procedures
- during evaluation and feedback
- as participants on management boards
- as members of advisory groups of people with disabilities
- in making decisions for themselves.

The concept of the “co-production” of support services has recently been promoted, bringing together the traditional organizations working on behalf of people with disabilities with organizations controlled by people with disabilities (164). It recognizes the contribution disabled people can make, based on their experiences, seeks to put disabled people in control of service developments and service delivery, and provides non-disabled people with the role of a supportive ally.

The advantages of co-produced service organizations are: the focus is on the needs of the users, and the combined resources improve the possibility of reducing disabling barriers and creating equality and interdependence (165). The principles of co-production and user involvement have been put into practice around the world by organizations of people with disability and by parents of children with disabilities, whether in formal service delivery or community-based rehabilitation (166).

**Mechanisms for independent living**

Randomized trials in high-income countries have compared personal assistance with usual care for children with intellectual impairments, adults with physical impairments, and older persons without dementia. Personal assistance was generally preferred over other services, had benefits for some recipients, and may benefit caregivers (118–121).

Personal assistance schemes are not limited to those with physical impairments. A range of approaches can benefit people with intellectual impairments or mental health conditions, including:

- **Advocates** – where the person is supported one-on-one by a trained and skilled individual to make and carry through a decision.
- **Circles of support** – networks of supporters and friends who know the person well and who can make decisions to which the person freely consents.
- **KeyRing** or living support networks – where people with intellectual impairments live in the community, but with a “community living worker” available to provide support and help make connections in the community.
- **User-controlled independent living trusts** – similar to circles of support, but with a legal structure that sets up the necessary framework of decision-making around the individual.
- **Service brokerage** – where a skilled supporter enables the person to choose services, helping with the assessment process and supporting implementation of assistance packages. An agency can act as the named employer of support on behalf of an individual, if required.

Despite evidence of the benefits of direct payments, mental health users are underrepresented in individualized funding arrangements in Australia, Canada, the United Kingdom, and the United States (167).

Because of the lack of funds, personal assistance is rarely publicly provided in low-income and middle-income settings. But some innovative programmes suggest that low-cost solutions can be effective and that independent living principles remain relevant (3).

- In 2003 in Brazil there were 21 centres for independent living, with the first in Rio de Janeiro, already been operating for 15 years
As elsewhere, the independent living movement brings together people from different impairment groups, and offers services such as peer support, information, training and personal assistance, with staff who themselves have disabilities. However, unlike those in developed countries, centres for independent living do not tend to receive money from the state, but instead have to raise their own funds, such as through employment brokerage services.

In the Philippines a national disabled peoples organization has developed a multi-sectoral programme in partnership with the Department of Education and the parents association. It supports the training of teachers and parents on providing appropriate personal assistance, so that children with severe impairments can attend local mainstream schools. It works with more than 13,000 children in rural areas, offering joint training workshops with preschool children, parents, and teachers.

Building capacity of caregivers and service users

Training for support workers

Support workers, regardless of setting and service, need professional training (variously known as human services, social work, or social care) that takes into account the principles of the CRPD. While many workers lack post-school education, further and higher education programmes in social work and health and social care are increasingly available in high income countries. The United Kingdom offers a National Vocational Qualification in health and social care, achieved through demonstrating competency at work and possession of background knowledge. Often, people with disabilities can complement any formal training with on-the-job instruction.

How the training is conducted is as important as the content. In general, people with disabilities prefer the personal assistance model where they direct the tasks, rather than have the social care worker provide the services. A new generation of support workers – including personal assistants, advocates, and those supporting people with intellectual difficulties – present a fresh approach to working with people with disabilities in the community and helping them attain their own goals and aspirations, based on respect for human rights rather than the traditional ethos of “care.”

Support for users of assistance and support services

Funding arrangements for personal assistance schemes must take into account the additional tasks that users of the schemes may be called on to perform. People receiving direct payments, for instance, should be properly supported so that complexities in the system are not the cause of additional stress or isolation. People with disabilities who employ support workers need to know how to manage staff and fulfil their employer responsibilities. A study in the United Kingdom found that 27% of people with disabilities employing personal assistants found becoming an employer daunting, and 31% found it difficult to cope with the administration.

Disabled peoples’ organizations and caregivers’ organizations help users benefit from consumer-directed services. Individualized funding models are most effective when coupled with other support services. Support is also needed to ensure that brokers and fund managers are not excessively directive and that the quality of care is good. Some disabled peoples’ organizations – such as the Scottish Personal Assistant Employers’ Network – have launched recruitment and training programmes aimed at personal support workers and their supervisors, as well as at their potential employers with disabilities and their families. In low-income settings, community-based rehabilitation programmes may be able to provide training to people with disabilities and their families to manage their support needs and create links with self-help groups for information and advice.
Developing community-based rehabilitation and community home-based care

**Community-based rehabilitation**

In many low-income and middle-income countries, consumer-led, government-delivered, or NGO-delivered community-based rehabilitation (CBR) programmes are becoming a source of assistance and support for many people with disabilities and their families. Many focus on information provision, working closely with families, and facilitating disabled peoples’ participation in the community (173). They can also counter tendencies towards overprotection by families. In all income settings, it may be useful for CBR workers, social workers, or community workers to bring together families who share similar experiences in supporting relatives with disabilities.

- In Lesotho the leaders of nine branches of the national association of parents of disabled children found that parents required support in how to teach, train and handle their child; information about the rights of people with disabilities and how to work with professionals; and information on how to create teaching aids and obtain equipment (174).

- RUCODE, an NGO in the state of Tamil Nadu, India, runs community-based day-care centres for children with intellectual disabilities and cerebral palsy, with the help of local government and parents. Each centre caters to around 10 children, with one teacher and one attendant at each centre and support from RUCODE staff. The community contributes the venue and provides lunch for the children.

- In Nepal CBR programmes are implemented in 35 districts by local NGOs, with the government providing funding, direction, advice, and monitoring at the national and district levels (175).

As the CBR model strengthens the quality of the relationship between people with disabilities and their families, it can bring significant support to people with disabilities and caregivers (176). Recently the principles of independent living have started to be introduced within community-based rehabilitation, which will help CBR services ensure greater self-determination for people with disabilities.

**Community home-based care**

Community home-based care is any support given, in their homes, to people who are ill and their families (177). The model, developed particularly to cope with HIV/AIDS, operates in many African and Asian countries, with care of orphans a special concern. A government community home-based care programme might provide food, transport, medication, respite care, cash allowances, and emotional and physical care.

**Including assistance and support in disability policies and action plans**

The inclusion of formal assistance and support services within a national disability policy and related action plan can improve community participation of persons with disabilities, for example:

- Australia’s Disability Discrimination Act (1992) encourages organizations to create action plans to eliminate discrimination in provision of goods, services and facilities (178).

- New Zealand’s Disability Strategy (2001) offers a framework for government to begin removing barriers to the participation of people with disabilities (179).

- Sweden’s “From Patient to Citizen” national action plan (2000) has a vision of complete access and seeks to eliminate discrimination at all levels (180).

CBR programmes can also promote local action plans in low-income and middle-income countries (181).
Conclusion and recommendations

Many persons with disabilities need assistance and support to achieve a good quality of life and to participate in social and economic activities on an equal basis with others. Across the world most of the assistance and support services are provided informally by family members or social networks. While informal care is invaluable, it is sometimes unavailable, inadequate or insufficient. Formal provision of assistance and support services, by contrast, is insufficient, especially in low-income settings: state supply of services is generally underdeveloped, not-for-profit organizations have limited coverage, and private markets rarely offer enough support to meet the needs of people with disabilities. The result is significant unmet need for assistance and support services.

A multitude of stakeholders have roles in ensuring that adequate assistance and support services are accessible to persons with disabilities. Government’s role is to ensure equal access to services including through making policies and implementing them; regulating service provision including setting standards and enforcing them; funding services for people with disabilities who cannot afford to purchase services; and if needed, organizing the provision of services. In planning and introducing formal assistance and support services, careful consideration should be given to avoiding disincentives for informal care. Service users and disabled peoples’ organizations and other NGOs should increase awareness, lobby for the introduction of services, participate in policy development and monitor implementation of policies and service provision. Service providers should provide the highest quality of services. Through international cooperation, good and promising cost-effective practices should be shared and technical assistance provided to countries that are introducing assistance and support services.

This chapter has discussed some of the models of organizing, funding, and delivering formal assistance and support services. No single model of support services will work in all contexts and meet all needs. Person-centred services are preferable, so that individuals are involved in decisions about the support they receive and have maximum control over their lives. The following measures are recommended for countries introducing or developing assistance and support services.

Support people to live and participate in the community

Provide services in the community, not in residential institutions or segregated settings. For countries that have previously relied on institutional living:

- Plan adequately for the transition to a community-based service model, including human resources and sufficient funding for the transition phase.
- Progressively develop and reallocate resources to build community support services, including the possible transformation of institutions into alternative care services such as resource or day care centres.

Foster development of the support services infrastructure

- Include the introduction and development of formal assistance and support services – customized to different economic and social environments – in national disability action plans to improve participation of persons with disabilities.
- Support the development of a range of providers – state, not-for-profit providers, for-profit entities, and individuals – and models to meet, in a cost-effective manner, the diverse assistance and support needs of people with disabilities.
- Consider a variety of financing measures including: contracting out services to private providers, offering tax incentives, and devolving budgets to people with
disabilities and their families for direct purchases of services.

- In low-income and middle-income countries, support service provision through civil society organizations, which can expand the coverage and range of services. CBR programmes have been effective in delivering services to very poor and underserved areas.

**Ensure maximum consumer choice and control**

This is more likely to be achieved by formal services when:

- Services are individualized and flexible rather than “one size fits all” agency-based and controlled services.
- Consumers are involved in decisions on the type of support and direct the care tasks wherever possible rather than being a passive recipient of care.
- Providers are accountable to consumers and their relationship is regulated through a formal service arrangement.
- “Supported decision-making” is available for people who have difficulties making choices independently – for example, people with severe intellectual impairment or mental health conditions.

**Support families as assistance and support providers**

Separate the needs and rights of informal caregivers from the needs and rights of persons with disabilities. A balance must be found so that each person has independence, dignity, and quality of life.

Promote collaboration between families and family organizations, governmental and nongovernmental organizations, including disabled peoples’ organizations, to provide support for families through a range of systems and services including by:

- Arranging for respite care, which can provide a short break from care and psychosocial counselling to improve family well-being.
- Providing direct or indirect financial support.
- Providing information about the services available for caregivers and people with disabilities.
- Organizing opportunities for families, who share similar experiences in supporting relatives with disabilities, to come together and offer mutual information and support.

Community-based rehabilitation workers, social workers, or community workers can provide these opportunities for families. Useful family-oriented approaches also include developing communities of care and social networks.

**Step up training and capacity building**

Effective assistance and support services require training of both care recipients and care providers, irrespective of whether the care is provided formally or informally.

- Formal support workers, regardless of setting and service, should be provided with relevant professional training, which takes into account the principles of the CRPD and preferably involves people with disabilities as trainers to sensitize and familiarize service providers with their future clients.
- Provide training to families on working with caregivers, defining roles, setting boundaries, and on how to empower their relative with disability.
- In low-income settings, community-based rehabilitation programmes can provide training to people with disabilities and their families to manage their support needs and create links with self-help groups for information and advice.
- Persons with disabilities directly employing support workers using allocated public funds may need training and assistance in recruitment, management and fulfilling their employer responsibilities.
- Training schemes for sign-language interpreters and advocacy workers will help improve supply of these vital personnel.
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**Improve the quality of services**

To ensure that formal assistance and support services are of good quality, the following are recommended:

- Develop sound and fair disability assessment criteria and procedures, focusing on support needs to maintain and improve functioning. Use ICF as a guiding framework in developing disability assessment criteria.
- Develop clear eligibility criteria for assistance and support services and transparent decision-making processes. In resource-constrained environments, focus on people with disabilities most in need of support services – those without any informal caregiver and limited means.
- Set standards of services, enforce them, and monitor compliance.
- Monitor service provision.
- Keep updated records of users, providers, and services provided.
- Ensure coordination across different government agencies and service providers, possibly through introducing case management, referral systems, and electronic record-keeping.
- Establish complaints mechanisms.
- Introduce mechanisms to detect and prevent physical and sexual abuse in both residential and community settings.
- Ensure that support staff have appropriate training, proper levels of pay, status, and working conditions.
- Encourage the monitoring of service quality by disabled peoples’ organizations and other NGOs.

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