**Call for inputs:** Re-Imagining Services in the 21st Century to give effect to the right to live independently and be included in the community for persons with disabilities.

**Purpose:** To inform the thematic report of the Special Rapporteur on the rights of persons with disabilities to live independently and flourish in their communities. A necessary part of this goal is to critically examine and re-imagine the service paradigm that has evolved up over the past several decades and to put in its place a new agenda for change that stands a better chance of realizing the underlying vision of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

**Date:** October 5, 2022

**Submitting organization:** Enabled Children Initiative, [www.enabledchildren.org](http://www.enabledchildren.org)

**About the organization:** The Enabled Children Initiative (ECI) is an independent non-profit organization registered in the United States as a 501(c)(3), with a branch office in Afghanistan (registration number 465), that supports children with disabilities in Afghanistan. Through our six programs across six provinces, we provide residential, educational, income generation support and emergency aid to children and youth living with disabilities in Afghanistan, and their families. Our vision is of a more inclusive Afghanistan, where persons with disabilities are embraced and respected by their families and communities, and have equal access to education, healthcare, and employment opportunities, to reach their full potential as human beings.

Our programs include private care home, with an in-home school, called Window of Hope, for orphans and abandoned children with disabilities. We run a school for children with disabilities, the Enabled Children School. We support families living in poverty to support their disabled child within the home and raise awareness in local communities, via our Community-Based Disability Awareness & Support Program. Our Social Integration program equips youth with disabilities with vocational skills and helps integrate them into society. Our Frozan Fund program provides income generation and emergency relief for families living in poverty, or affected by natural disaster, who have a child or family member with a disability. We also advocate for the rights of persons with disabilities in Afghanistan, helping families understand their child’s rights, get children enrolled in school, or access healthcare and treatment.

**Part A: Policy Goals and Principles**

*Questions:*

1. What are the primary principles and goals that govern the provision of services to people with disabilities in your State? (see response below)

2. Have these principles and goals been modified to take explicit account of Article 19 of the CRPD on the right to live independently and be included in the community (e.g., personalization of services, personal and human support, assistive technology, accessible transport, access to housing, expansion of community-based services, emphasis on personal empowerment and choice). (see response below)

3. Are these goals linked directly to broader policy imperatives to ensure people with disabilities can take meaningful advantage of being in the community – such as the opportunity for employment and education, access to health care, promotion of natural or unpaid supports or community assets available to citizens without disabilities? If so, how? (see response below)

*Responses:*

From 2004 until 2021, Afghanistan took many important steps toward inclusion of persons with disabilities. Afghanistan signed and ratified the Convention on the Rights of Persons with Disabilities (CRPD), as well as its Optional Protocol, on September 18, 2012. The 2004 Constitution of Afghanistan states that Afghan citizens are equal and cannot be discriminated against based on disability. Article 53 of the Constitution provides for financial aid to persons with disabilities and guarantees their “active participation and re-integration into society.” Article 84 provides for two persons with disabilities to be appointed by the President as Members of Parliament in the House of Elders.

Afghanistan also signed on to other conventions that referenced equality and inclusion for persons with disabilities, including the UN Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on Cluster Munitions, the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on their Destruction, the Proclamation on the Full Participation and Equality of People with Disabilities in the Asia Pacific Region, and the Biwako Millennium Framework for Action Towards an Inclusive, Barrier Free and Rights Based Society for Persons with Disability.

A lot of effort went into drafting and adopting laws, policies, and plans for the inclusion and equality of persons with disabilities, namely, a National Policy for Persons with Disabilities (2004), and a National Strategy for Disability and Rehabilitation (2013-16). A National Law of Rights and Benefits of People with Disabilities secured 3% of jobs in the public sector for persons with disabilities. The Ministry of Education also drafted an inclusive education policy.

However, despite all this progress on paper, not much was done to actualize the articles of the CRPD and the laws and policies in terms of actual programming or budgeting to support those programs. Disability was never a national priority and in an environment of competing development priorities, it was often not seriously considered by donors or the government.

Now, following the collapse of the Islamic Republic of Afghanistan in August 2021, the international conventions, laws and policies, and even protections afforded in the Constitution, are all in question and it is not clear whether or not they remain in effect.

While progress on paper has swiftly digressed, the day-to-day situation for persons with disabilities has only gotten worse over the past year. On top of continuing violence and political uncertainty, Afghanistan is in the midst of a terrible humanitarian crisis, triggered by the change in regime in August, the sudden cut in the international community’s donor funds for government services, freezing of the country’s financial assets, and a continuing drought. These changes have triggered a massive reduction in public health, education, and other support services; wide-scale unemployment; escalating food and commodity prices; and nationwide food shortages.

The United Nations predicts that 18.4 million people in Afghanistan (over half of the population) will require humanitarian assistance this year, and 634,800 Afghans will be displaced from conflict this year. Furthermore, a World Food Program household survey of 1,600 Afghans conducted in September 2021 indicated that as much as 95% of respondents did not have enough to eat each day. Families need food and supplies for winter.[[1]](#footnote-2)

People living in poverty who are disabled were already vulnerable, especially children, but under these new desperate circumstances, their vulnerability has only increased. Enabled Children Initiative has received reports of poor families migrating and abandoning severely disabled children on the roadside, as well as increased requests for basic support in the form of food and blankets.

Afghanistan is still also one of the most heavily-mined countries in the world. Many children suffer from war-wounds and become amputees in terrorist attacks and mine explosions. According to the UN Mine Action Service (UNMAS), improvised explosive devices (IEDs) caused 98% of casualties recorded in 2019, 78% of those casualties were children.[[2]](#footnote-3) This has not changed—Enabled Children Initiative has received reports of children who recently stepped on unexploded ordinance and became amputees.

Afghanistan also continues to be one of the least developed countries world-wide. Though major advancements were made in prenatal and maternal healthcare over the past 20 years, lack of access to prenatal care and birthing centers add to an increased number of children born with a congenital disability. Those advancements have also been steeply and suddenly cut back following the political collapse of August 2021.

Data shows that under these desperate conditions, persons with disabilities suffer disproportionally. Afghanistan has one of the highest proportions of people with disability globally. At least one in five households contain an adult or child with a physical, sensory or psychosocial disability. More than one million Afghans also suffer from amputated limbs, mobility, visual or hearing disabilities.[[3]](#footnote-4)

The Asia Foundation Model Disability Survey for Afghanistan, published in May 2020, showed that 17.3% of children, and 80% of adults, have some form of a disability, with prevalence higher in women.

A recent report by Save the Children published in August 2022 about how the humanitarian crisis in Afghanistan has affected children over the past year shows that children with disabilities are the most vulnerable and adversely affected. The report showed that Afghan families with disability in their household are most likely to have children resorting to hard labor to make ends meet and were four times more likely to have lost their income over the past year.[[4]](#footnote-5)

Stigma around disability also means that discrimination is rife in public and in families. Lack of public awareness of the causes and nature of disability means that some families regard children with a disability as a curse or a punishment upon the family or the mother who bore the child. These children are unlikely to receive any therapy, assistance or basic education, and many are shut away in their homes or tied up while parents must leave the house to work, a situation that is exacerbated by high poverty rates in Afghanistan. For many families, particularly in urban areas and those living in poverty, the pressure of raising a child with a disability is overwhelming and some resort to abandoning their children.

Enabled Children Initiative firmly believes that the best way to ensure that a person with a disability will have a dignified life, be respected by their family and community, and get access to a pathway to education, healthcare and employment, is by reaching families who have a child with a disability from a young age, and assisting and supporting that child and their family. Breaking down stigma, increasing understanding, and helping children access healthcare, education, and other services early in the child’s life is the best way to ensure that the child will have a dignified and fulfilled life, and better chance of gaining employment, becoming contributing members of society, and living as independently as possible later in their life.

**Part B: Service Delivery**

4. Who primarily delivers services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?). How do you see this mix changing if at all as a result of the UNCRPD in your country?

*Response:*

Though the Afghan government’s Ministry of Martyrs and Disabled is responsible for coordinating disability-related affairs in the country, as well as dispersing the pension for persons with disabilities who qualify, most of the service provision comes from local Afghan NGOs or International NGOs operating in Afghanistan. This includes a largely uncoordinated mixture of physical rehabilitative services, medical care and treatment, special education and community-based education and rehabilitative programs, prosthetics and physical therapy, and vocational training for persons with disabilities. For example, the International Committee of the Red Cross has five regional centers which provide rehabilitative services. The Enabled Children Initiative is a small INGO that provides special education services, community-based family support services, emergency aid support to families with a disability, and emergency residential support to abandoned disabled children, in six provinces of Afghanistan.

5. Who primarily pays for services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?). How do you see this mix changing if at all?

*Response:*

Before the collapse of the government in August 2021, the Afghan government received 70% of its national budget from the international donor community. There was also a vibrant donor community funding smaller Afghan NGOs across the country that were providing limited services. Since August 2021, the international donor community has largely ceased funding initiatives in Afghanistan, except through the UN and WFP. Many small Afghan NGOs who relied on international donor funding have ceased operations, and many national programs (e.g., education and healthcare) are now unfunded. This means that the few existing services for persons with disabilities that were being offered before 2021 have now largely disappeared, except for some basic services provided by large INGOs like physical rehabilitation provided by the International Committee of the Red Cross.

The Enabled Children Initiative has maintained and expanded its programs over the last year mainly because the organization did not rely on any international country donors to sustain its work, so we were able to maintain our funding streams despite the political changes in the country.

6. Describe generally how community-based providers are paid for the services they deliver (e.g., through general grants, through per capita funding, based on specific services rendered, other means?). What changes, if any, are anticipated regarding the present payment methodology? NA

7. In what ways are principles and service goals communicated to the service system (e.g., in laws, service standards, staff training, funding incentives, means for compensating/penalizing service providers, and/or for assessing the quality of services?). Please describe. NA

8. What new services, including those to support families, have been added to the available service array to advance principles consistent with Article 19? NA

9. What practices, if any, have been adopted/encouraged to promote greater use of technology to personalize support to persons with disabilities (e.g., telehealth, remote monitoring, adaptive communication, artificial intelligence, etc.)? NA

10. In what ways are caregivers (e.g., family members, other informal caregivers) recognized and supported?

*Response:*

The questions about the recognition and support of caregivers is important, as caregivers are almost never factored into programming approaches in Afghanistan. Because Enabled Children Initiative works mainly with children, all our programs take a family-focused approach, working directly with caregivers on training, awareness raising, and supporting them with cash assistance. This approach ensures increased awareness and understanding of disability within the home, helps break down stigma, and equips caregivers with the long-term skills needed to care for their child or family member at home.

11. Do you have a policy of personalizing/tailoring services to individual needs? How is the policy implemented? (e.g., through individual planning requirements? etc.).

*Response:*

Enabled Children Initiative takes a personalized, individualized approach to each child and family we engage. In coordination with families, and following assessments by our psychology and physiotherapy teams, as well as our community-based mobilization teams, our team creates a plan for each child that includes goals our team can help families achieve. This is the approach at our special education school, in our community-based disability awareness and support program, and at our emergency residential center for abandoned children with disabilities. Each plan is tailored around the specific needs of each child. Another reason for this is that it is extremely difficult in Afghanistan to get accurate diagnoses for disability, so most of the children we work with have either never been diagnosed or improperly diagnosed. Thus, a tailored approach to each child ensures that our assistance and support to that child will be most effective.

12. Describe how much control people with disabilities have regarding the services that they receive (e.g., choice of who provides support, choice of where they live and with whom they live, control over budgets).

*Response:*

In Afghanistan, there are extremely limited choices for persons with disabilities when it comes to education, employment, healthcare, and other forms of social services and support. Eighty percent of the Afghan population live in rural areas, and many families will travel for days and spend significant amounts of money to bring their child or family member with a disability to a regional center for treatment, which are largely limited to physical rehabilitation centers. Schools that will admit children with disabilities are almost non-existent and depend entirely on the willingness of the respective school’s administration as to whether they will admit a child with a disability. In terms of independent living options, the concept of independent living is not within the cultural context of Afghanistan, where it is the norm for large extended families to live within the same dwelling. There are no independent living centers in Afghanistan. Thus, the approach of Enabled Children Initiative is to help create safer spaces for children with disabilities within their own homes, equip parents and caregivers with the tools they need for proper care, and help children with disabilities access services for education, health, and treatment.

13. In some disability support structures, service users or families have an allocated budget which is devolved so they have control over how the funds are used to purchase eligible disability supports. Do you have or anticipate a policy of devolving budgets to the service user? Describe.

*Response:*

In Afghanistan, persons with disabilities are entitled to a modest pension from the government. That pension was being disbursed to a number of eligible persons before the collapse of the government in August 2021; however, it was not a sustainable approach because if every eligible Afghan had been accessing the pension, the required budget would have been untenable for the government to maintain. Following the collapse of the government, and the disappearance of international donor funds to the government, there is simply no funding available for this program.

As part of its community-based disability awareness and support program, Enabled Children Initiative disburses a modest cash stipend to families who are enrolled in the program, which is disbursed in three installments over the course of the three-month program. The cash stipend is intended to be utilized at the family’s discretion toward the care of their disabled child. For example, some families have used this to purchase nutritious food and clothing for their child, or pay for medical bills for their child’s care.

14. If budgets are devolved to the user, what kinds of supports are available to assist them, how are the administrative tasks minimized and is the individual given wide discretion on how the funds are spent?

*Response:*

Enabled Children Initiaitve also refers families enrolled in programs to other organizations within our network who can provide further in-kind support to families who have a disabled child, including for physiotherapy sessions and training, provision of assistive devices, construction of accessible living spaces, corrective surgeries, or emergency healthcare.

15. Have you adopted any positive “wealth accumulation strategies” (e.g., innovative trust funds) to complement social provision? Describe. NA

**Part C. Monitoring and Oversight**

16. Describe the types of data you collect on people with disabilities receiving services (e.g., numbers of service users, types of disability, service utilization, costs per person, quality of life outcomes, health outcomes, incidence of abuse, neglect and exploitation). Are these data gathered and reported in aggregate only or may it be disaggregated per person?

*Response:*

Enabled Children Initiative maintains detailed case files for each family and child we are supporting. Our team conducts an initial survey to ensure the family is eligible for our programs, whether that is enrollment at our school or enrollment in our community-based program. Once a child/family is enrolled, we create a detailed case file that includes a range of information including but not limited to: the child’s age, type, cause and symptoms of disability, any past treatments, therapies or surgeries received, use of assistive devices, access to education, healthcare, and other relevant services, socio-economic information about the family, level of income, family’s understanding of disability, actions and approaches taken by the family in the care of their child, services available within the community, etc. The data is further updated with information about the child’s progress, which services the child and family has received, if the child has been referred, and other detailed notes about the child’s progress. This data is maintained in a database and disaggregated per person.

17. How do you enforce standards as they apply to service delivery providers (law, standards, incentives)? What do these standards focus on in the main? How are they measured?

18. Do your compliance rules make it possible to disqualify those providers in breach of the standards from competing for future State support? NA

**Part D. Re-Shaping the Market/Challenges and Opportunities**

19. Describe the major challenges you face in endeavoring to reform your system of services and supports for people with disabilities. Barriers might include workforce shortages, inadequate

resources, lack of knowledge and training, weak infrastructure, and/ history of

institutionalization.

*Response:*

There are numerous challenges in reforming service systems and supports for persons with disabilities, not just for NGOs and INGOs doing service delivery, like Enabled Children Initiative, but also at the state-level in Afghanistan. Some of the daily challenges faced are political instability, insecurity and violence, shortage of funding and resources, shortage of trained staff, limited knowledge-building and training opportunities, and a mass humanitarian crisis that has led to an increase in the abandonment, abuse and neglect of people with disabilities, with children suffering exponentially.

On a national level, the political instability and insecurity in Afghanistan means that reform progress made at this level can be and has been wiped out overnight. 20 years of progress in terms of policy and legislation was off-railed suddenly with the change of regime. This further highlights the need for community-based, grassroots approaches run by Afghans to supporting persons with disabilities, that can withstand and weather the constant changes in the country.

20. How is the COVID-19 pandemic and its aftermath reshaping the service delivery market?

Explain in terms of changes in service expectations among service recipients and regarding

impacts on the services available.

*Response:*

The range of crises in Afghanistan over the past year put COVID-19 at a lower priority than in other countries. The humanitarian crisis, government collapse, and continuing violence have dominated the agenda in Afghanistan. However, in 2020 when the COVID pandemic initially hit Afghanistan, government schools closed for a period. Instead cut contact with our students and families, the closure forced Enabled Children Initiative to re-think its approaches and come up with new ways to keep our students engaged and learning while having to remain at home, so that they did not regress.

At our school, we ended up starting home visits, where mini teams including a teacher, psychologist, and physiotherapist would visit students and families in their homes. Alongside these home visits, we invited smaller groups of students and parents into the school each week for teaching, psychology, and physiotherapy sessions, while maintaining social distancing. The changes forced on us by COVID-19 ended up having a positive impact in the way we deliver services—the home visits were extremely well-received and we saw positive outcomes, so we continued those home visits even after schools re-opened.

21. Do you pro-actively seek out new kinds of service providers with new business models that

emphasize person-centered practices?

*Response:*

Yes. We seek partners that value our core belief— “disability is not inability” —and put the dignity and agency of the person with disability at the center of their work.

22. Do you encourage service providers to adopt a ‘business and human rights approach’ to their

endeavours? NA

23. How do you incentivize innovative person-centered new providers to enter the market?

Describe. NA

24. Do minimum wage laws apply in this sector? Is there a career advancement structure for

workers in the sector? NA

**Part E: Process of Reform**

25. What lessons have been learned to build momentum, while minimizing resistance, for systems change consistent with Article 19? NA

26. Did you have have an initiative to re-imagine services that includes service users (e.g., have you commissioned a Task Force?). NA

27. In what ways do you solicit the input of people with disabilities and family members in policy making, program oversight, strategic planning, etc. (e.g., national advisory councils, regional/local forums, surveys, webinars, etc.). NA

28. What are the two or three strategic objectives you have to enhance the quality, availability, and effectiveness of services to people with disabilities in your state? NA

1. Afghanistan- Complex Emergency, USAID, September 24, 2021: https://www.usaid.gov/sites/default/files/documents/2021\_09\_24\_USG\_Afghanistan\_Complex\_Emergency\_Fact\_Sheet\_7.pdf [↑](#footnote-ref-2)
2. UNMAS Afghanistan Programme, <https://unmas.org/en/programmes/afghanistan> [↑](#footnote-ref-3)
3. [i] Human Rights Watch (2021) Afghanistan: Women with Disabilities Face Systemic Abuse: Barriers, Discrimination in Healthcare, Education <https://www.hrw.org/news/2020/04/27/afghanistan-women-disabilities-face-systemic-abuse>. [↑](#footnote-ref-4)
4. https://resourcecentre.savethechildren.net/document/breaking-point-childrens-lives-one-year-under-taliban-rule/ [↑](#footnote-ref-5)