Rural disabled women’s social inclusion in
post-armed conflict Sri Lanka

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### Acronyms and abbreviations

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<tr>
<td>AKASA</td>
<td>Association of Women with Disabilities (Sri Lanka)</td>
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<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities (United Nations)</td>
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<tr>
<td>CSI</td>
<td>Centre for Social Impact, UNSW</td>
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<tr>
<td>FGD</td>
<td>focus group discussion</td>
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<td>MSSSW</td>
<td>Ministry of Social Services and Social Welfare (Sri Lanka)</td>
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<td>LLRC</td>
<td>Lessons Learnt and Reconciliation Commission (Sri Lanka)</td>
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<tr>
<td>LTTE</td>
<td>Liberation Tigers of Tamil <em>Eealam</em></td>
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<tr>
<td>Rs</td>
<td>Sri Lankan rupee</td>
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<td>SSA</td>
<td>Social Scientist’s Association of Sri Lanka</td>
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<td>UNSW</td>
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Acknowledgements

Several women with disabilities living in the rural areas of the North Central Province and the Eastern Province of Sri Lanka gave of their time and willingly shared their life experiences during the field work carried out for this study. Many of them travelled a long distance to meet with the researcher in a context where public transport does not provide any accessible facilities for people with disabilities.

Ms N Kamala, Ms Kala and the other staff at AKASA (Association of Women with Disabilities) efficiently organized the interviews, transport on site and in general facilitated the field work. Ms Kala translated from Tamil to Sinhala when required.

Mr Amalan Premkumar, Ms Kethmini Dharmasena, Mr Chamaka Ambagahawita and Mr Mark Schubert translated and transcribed the interviews.

The University of New South Wales (UNSW) vetted the ethics of this research work and provided the funding that made the field work possible. The Social Scientists’ Association (SSA) provided a partner institution through which the local researcher, Dr Dinesha Samararatne (SSA), could collaborate with the overseas researcher, Dr Karen Soldatic, of the Centre for Social Impact, UNSW Australia.
Executive Summary

This report describes the lives of women living with disability in rural Sri Lanka and is based on field work carried out in the North Central Province and Eastern Province of the country. The selection of these two provinces was based on the field presence of AKASA, the Association of Women with Disabilities, a small rural disabled women’s advocacy group. The methods of data gathering focused upon group discussions and in-depth interviews.

The findings that emerged from the qualitative data relate to several spheres of life: the personal, the family, the community, administrative regulations and the law. It was evident that ‘disability’ was not clearly identified as an abnormality. Rather, at the personal and the family level women living with disability had been encouraged to live a ‘normal’ life, coping as much as possible with their disability in environments that were not particularly accommodating of disability. This approach to disability is almost completely reversed at the community level where women experience marginalisation and other forms of restriction due to negative socio-cultural constructions of disability. According to the findings that emerged from the analysis of the interviews, the application of administrative regulations is irregular and, in certain cases, the scope of the regulations themselves was not clear to the stakeholders. Awareness of the applicable laws and the relevance of the human rights discourse to disability was low among the women who were interviewed.

The findings from the interviews with women from the Eastern Province provided insight into the impact of the internal armed conflict on women living with disability. The armed conflict both caused disabilities and minimised the possibility of empowering women to live with disability. In the post-armed conflict context, due to interventions by non-governmental organisations and the more stable provision of services by the state, the quality of life of women living with disability has improved comparably. It was also evident that women from the two different ethnic groups, Sinhala and Tamil, were able to bridge the gap between them by working together in addressing the issues they faced due to their disabilities.

A significant limitation of the findings of this report is the limited range of impairment type among the research participants. The women with disabilities interviewed for this research predominantly self-described as having a physical impairment. The life experiences of rural women living with cognitive and/or intellectual impairments are under-represented within the findings.
Rural disabled women’s social inclusion in post-armed conflict Sri Lanka

01. Background
Over recent years disability has become a core concern of global, national and local development initiatives. Global development institutes and donors are increasingly targeting this area for development investment as it is now well recognised that disability inclusion is integral to securing processes of community peace building for long-term sustainable social cohesion.\(^1\) A growing body of scholarly research and development practice initiatives have emerged in the area in response to this new agenda.\(^2\) Despite these growing efforts, rural disabled women remain the most marginalised from both the nascent scholarly research in the area and the field of disability inclusion social policy and practice. They are also the most vulnerable group within the post-armed conflict situation, experiencing the highest levels of gender-related violence, abject poverty, stigmatisation and exclusion.\(^3\) There is an urgent need to understand the impact of disability development initiatives on rural disabled women in post-conflict settings, these women’s subjective experiences of these initiatives, and the extent to which these initiatives achieve as well as do not meet the desired goals of inclusion and participation that are ostensibly aimed at alleviating disability poverty.

This report, a preliminary research project based in rural Sri Lanka, aims to begin to address this significant gap and inform emerging scholarship, policy and practice in the area.

1.1. Research project
This project is a result of a collaborative partnership between three institutions, represented by Dr Karen Soldatic of the Centre for Social Impact at the University of New South Wales (UNSW), Australia; Ms N Kamala of the Association of Women with Disabilities (AKASA) in Sri Lanka; and Ms Dinesha Samararatne of the Social Scientists’ Association of Sri Lanka (SSA). The objective of this project is to study the lived experience of disability among rural women with impairments (congenital and acquired) in Sri Lanka and it is intended as a preliminary exercise that will be followed by more detailed research work. Based on the findings, the researchers (Dr Soldatic and D Samararatne) hope to publish two articles: one focusing on the regulatory aspects of the experiences of women with disability in rural Sri Lanka and the other focusing on the sociological implications of the research findings. This research is being funded by UNSW through Dr Soldatic and the ethics approval for the project was obtained from the same university.

Disability studies in Sri Lanka is at a nascent stage, especially in relation to ‘non-medical’ aspects. There are only a few instances of research on law, policy and rights in relation to disability. That body of research concentrates on the legislative and administrative policies on disability in the country. The actual impact of those laws and policies on the lives of people with disabilities remains to be studied. Furthermore, the lived realities of particular vulnerable groups among people with disabilities are also yet to be researched and critically reflected on.

This project seeks to respond to this gap in knowledge by studying the life experiences of selected women with disabilities in selected rural districts in Sri Lanka in the post-armed conflict context. The study involved women from both the Sinhala and Tamil communities with the additional intention of studying their experiences of disability in relation to the armed conflict.

1.2. Country profile
Sri Lanka is now a middle-income country, with a population of about 21 million. The majority of people in Sri Lanka identify themselves as Sinhalese (70%) while Tamils (12%) and Muslims (7%) are the two main minority communities in the country. Since the 1940s, health care and education up to tertiary level have been provided free of charge. Within the South Asian region, Sri Lanka is considered to have reached a commendable quality of life. Life expectancy, for example, is 75.1 years and 95.6% of the population is literate.

In May 2009, the Government defeated the Liberation Tigers of Tamil Eealam (LTTE) in a long, 30-year internal armed conflict, in which the LTTE fought for a separate state in the north-east of the island. Political representatives of Tamils in this area had claimed they were being discriminated against because of their ethnicity. In the period since the armed conflict, questions have been raised (locally and internationally) about the conduct of both parties in the last phase of the war. Several resolutions have been adopted in the UN Human Rights Council regarding accountability and reconciliation in Sri Lanka over these incidents. A panel appointed by the UN Secretary-General concluded that there are credible allegations of violations of international humanitarian law and human rights law during the last phase of the war. A committee appointed by the Office of the High Commissioner of Human Rights is to commence its investigations into the allegations.

Partly due to international pressure to establish a domestic mechanism for inquiry and investigation into these alleged human rights violations, the Government appointed a commission of inquiry in 2010. War-related disability and trauma has been identified as a serious issue among the war-

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affected population. The Lessons Learnt and Reconciliation Commission (LLRC) in its report addresses disability specifically in relation to the armed conflict. It notes that disability has a ‘serious economic impact on the survival of the family’ and that the needs of people with disability require ‘special and urgent attention’ from the state. The Commission recommended, among other things, that the state should ratify the UN Convention on the Rights of Persons with Disabilities (CRPD) and introduce legislation to ensure respect for the rights of people with disabilities.

Alongside this turn of events, the Government of Sri Lanka has adopted a particular model of development for the country in which large-scale infrastructure, incentives for foreign direct investment and the promotion of tourism play a significant part. The Government has been subject to criticism locally and internationally in the pursuit of these development policies due to the ways in which these policies are undermining democratic governance, politicising public institutions and centralising political power.

1.3. Disability, women and ‘the rural’

According to the Ministry of Social Services and Social Welfare (MSSSW), about 7% of the Sri Lankan population lives with disability. Identifying the ‘disabled constituency’ of Sri Lanka is difficult, however, as Campbell notes, due to lack of information; she estimates its incidence to be anywhere between 5% and 20%.

Due to cultural stereotypes of gender, women are subject to marginalisation and discrimination. It is often stated that in Sri Lanka, women are relatively more empowered than their regional counterparts due to their high level of literacy and access to health care, education and employment opportunities. Yet, more discerning studies have demonstrated that women’s situation in Sri Lanka is perhaps not as advantageous as it seems. For instance, even though Sri Lankan rural and urban women are generally literate and educated, their political participation remains negligible and they do not reach the highest levels of leadership whether in the public or private sector, barring some exceptions. Within existing family law, there are several provisions which perpetuate patriarchy and the discrimination of women. Substantive equality, therefore, remains a significant challenge for Sri Lankan women. This is heightened in rural areas where there are fewer opportunities for economic empowerment of women, and fewer opportunities for tertiary education.

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The official definition of ‘rural’ in Sri Lanka is that given by the Department of Census and Statistics. Accordingly, all areas that are not declared as Municipal or Urban Councils are considered to be ‘rural’. Rural areas within Sri Lanka are also categorised by their distance from the primary urban centres, such as Colombo, Jaffna or Galle, alongside their heavily reliance on an agrarian economy based around farming.

1.4. Disability legislation and policy

Sri Lanka has signed but not ratified the Convention on the Rights of Persons with Disabilities. It has ratified, without reservations, all the other major human rights treaties including two optional protocols.

All government policies, programmes and regulations on disability are implemented through the MSSSW. A national policy on disability was adopted by the Government in 2003 and a draft National Action Plan on disability was proposed by the ministry in 2013. These policy documents recognise the rights of people with disabilities and undertake commitments to ensure their dignity and respect. As is demonstrated in this report, however, the implementation of this policy and action plan has been unsatisfactory.

The Sri Lankan Constitution contains a chapter on Fundamental Rights. The infringement or imminent infringement of those rights by executive or administrative action can be challenged before the Supreme Court by the victim or her attorney-at-law within 30 days of such alleged violation. This chapter, reflecting the dominant political thought at the time of its adoption, contains only civil and political rights. The only reference to disability is found in relation to the right to equality, wherein this right shall not prohibit any special measures being adopted for ‘women, children and disabled persons’. Recent jurisprudence of the Supreme Court has restricted the scope of this provision, however, and caused confusion as to its meaning. In determining the constitutionality of a draft legislation which, among other things, provided for voluntary quotas of women and young people in nomination lists for elections to local authorities, the Court observed that article 12(4) could not be used as a ‘sword’ but as a ‘shield’.

The other known instance of a Supreme Court ruling on disability is in the case of Ajith Perera v Attorney General. A disability rights activist petitioned the Court claiming a violation of his right to equality due to the non-implementation of the regulations of the MSSSW in 2005 and 2006. The Court held with the petitioner and ordered that all new public buildings should conform to the

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12 Department of Census and Statistics, ‘Concepts and definitions’.
13 Chapter 3 of the Constitution of Sri Lanka 1978 (herein after ‘the Constitution’).
14 Article 126 of the Constitution.
15 Article 12(4) of the Constitution.
relevant regulations. In practice, however, these regulations and the Supreme Court orders continue to be ignored.

There are several laws pertaining to disability in Sri Lanka but none of them adopt a rights-based approach.\textsuperscript{18} The main law relating to disability, the \textit{Protection of Rights of Persons with Disability}, prohibits discrimination on the basis of disability only in situations of employment and access to public places.\textsuperscript{19} Violations of this provision can be challenged before the High Court but there are no known successful cases.

\textbf{02. Methodology and Methods}

The research for this project was carried out within a framework of grounded theory. Grounded theory is a particularly qualitative methodology which seeks to develop conceptual knowledge and frameworks that are grounded in the individual experience of research participants. As a methodological approach it allows researchers a great level of flexibility in the analytical process, to build mid-range theories in new and novel research contexts. The generation of theory is thus an inductive process, derived by the generation of data. The approach is frequently used in social justice research where the ‘voice’ of the participants is foregrounded as the central guiding principle of the research strategy. The aim, therefore, is to develop a theoretical framework from research participants’ experiential understanding of the specific contextual circumstances in which they find themselves as subjects.\textsuperscript{20}

Through two focus group discussions (FGDs) and 13 individual interviews, qualitative data was gathered for the purpose of understanding the experiences of women with disabilities in rural Sri Lanka in selected communities, both Sinhala and Tamil. The methods employed for the research, including the questions asked at the FGDs and the individual interviews, were approved by the Ethics Review Committee of UNSW. The questionnaire and the information and consent forms were translated into both Sinhala and Tamil. All participants gave their consent to participate in the research by signing the consent form.

AKASA organised the FGDs and facilitated the individual interviews. All the women who were interviewed were members of AKASA. The women were from rural areas in the North Central, Central and Eastern provinces of the country. Their ages ranged from the 20s to 60s.

\textsuperscript{18} These laws include \textit{Mental Diseases Act No 27 of 1956}; \textit{Rana Viru Seva Authority Act No 54 of 1999}; and \textit{Election (Special Provisions) Act No 28 of 2011}.

\textsuperscript{19} Section 23 of the \textit{Protection of Rights of Persons with Disability Act No 28 of 1996} as amended.

Both the focus group discussions and the in-depth interviews had to be conducted based on the ability of the interviewee to comprehend and respond to the questions. In some instances, the interviewees responded positively and participated actively in the conversation. In other cases, the ability to comprehend the questions was low and hence the responses were not very articulate.

Most of the women who were interviewed had physical disabilities. There were two instances where the mothers of children with intellectual disabilities were interviewed. In the case of two women who could not speak, their mothers translated their sign language. The interviews were carried out by Dinesha Samararatne, who has a good knowledge of Sinhala and a working knowledge of Tamil. Where necessary, she was assisted by a translator in interviewing the Tamil-speaking women.

03. Limitations of the Research
The findings of this research may be limited by three factors. The first is that rural women with intellectual and/or cognitive disabilities were not interviewed for this study. The reason for this absence is not clear. The recruitment of research participants was via the rural disabled women’s advocacy group AKASA, who provide advocacy and service support to women with a diverse range of impairments, including women with cognitive and/or intellectual disability. This is a significant gap in the findings as Sri Lankan research suggests a significant prevalence of intellectual disability. Second, this research uses a grounded theoretical methodological approach and, therefore, the findings are limited to the experiential understanding of the group of women with disabilities who participated in the focus groups and in-depth individual qualitative interviews. Therefore, the findings cannot be extrapolated/generalised to all rural disabled women living in Sri Lanka. Third, most of the women were interviewed in a fairly formal context where clearly the researcher had significant power. While the researcher aimed to be critically reflexive throughout the interviews, clearly the long historical context of ethnic conflict may have strongly influenced or constrained the information provided by the research participants. It is not possible to assess whether this context influenced their responses to the questions posed.

04. Research Findings
The emergent research themes, from the qualitative analysis, provides insight into the intersectionalities that shape women’s experience of living with an impairment in a rural, post-armed conflict context, among them disability, gender, power, culture and governance. These interstices will be scrutinised in greater detail at a later time. For the purpose of this report, we present an overview of the different themes and threads that dominated the narratives of the women with disabilities interviewed at each of the research field sites.

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21 See, for instance, C Rodrigo et al, ‘Symptoms of anxiety and depression in adolescent students; a perspective from Sri Lanka’, 2010.
4.1. Privacy, intimate relationships and disability
The women interviewed found it difficult to protect their privacy and physical/emotional integrity from the world at large. This was mainly due to the natural and built environments in which they lived. This environment restricts them and forces them to depend on family members, members of the community and even, in certain cases, on total strangers. Two commonly faced problems are the lack of accessible modes of transport and the lack of accessible sanitation facilities. One woman related how she had visited a public place and was informed that a newly built accessible toilet was available for her use. However, when she approached the unit she found that it was locked. Her accompanying family members had to speak to the establishment, who in turn had to call the person who carried the key so the toilet could eventually be unlocked. By then, according to the woman, everyone in the vicinity was aware that she needed to use the toilet, which she found embarrassing. If the toilet had been accessible both in its structure and how it was managed, she could have used it without having to embarrass herself and depend on others to make that unit accessible. It must be noted that, even where the built environment is accessible, a disregard for the dignity and autonomy of a potential user can place them in a situation that is unacceptable.

Another aspect of privacy and autonomy described by the interviewees was in the area of intimate relationships. Due to the dominance of stereotypes of ‘ableism’ and ‘womanhood’, women with disabilities feel insecure about forming intimate relationships. Some had found male partners who themselves had impairments. Others who had married partners without an impairment stated that they were grateful to their partners for accepting them. Some women stated that they felt lonely and felt a need for companionship and love but, at the same time, they were afraid of entering into a relationship due to the fear of rejection or abandonment given broader socio-cultural stigma attached to disability. One interviewee pointed out that a woman was marginalised in the realm of sexual activities, due to the stereotyping of ‘beauty’ and ‘womanhood’.

4.2. Disability and understandings of ‘normality’ in the rural family
According to the women interviewed, their experience of disability was not necessarily contrasted against a notion of ‘normality’. It was repeatedly stated by the interviewees that they did not feel they were particularly different from their family members. They also said they were expected, as far as it was possible, to contribute to the running of the household, for example by cooking, cleaning and contributing in any other possible way. Many also stated that they were not treated differently in school (further discussed in section 4.5).

As researchers, this finding was surprising as other instances suggested that rural Sri Lankan women with disabilities are readily treated differently due to familial and community perceptions surrounding disability and, in turn, familial assumptions around the women’s capabilities to participate within their households and communities. The reasons for not being treated differently within the home were not very clear. According to some of the women with disabilities interviewed, it was because the family had a positive attitude towards their capabilities and did not want to
undermine the person concerned by lowering their expectations of her. As researchers, we also reason that no individual could be released from contributing within the home because in rural communities, all activities are labour-intensive (from earning a livelihood to running the household) and therefore require assistance from all household members where possible. Moreover, many of the women’s households were extremely poor with few, if any, material means to purchase additional household supports to undertake such tasks. Another possible reason could be that within the private sphere, even a woman with a disability is expected to conform as far as possible to the stereotype of the woman as ‘the home-maker’. This is an area that requires greater sociological research to gain greater understanding and insight into these processes of meaning.

Regardless of the contributing factors, it was evident that not being treated differently created a sense of self-worth and security in these women. Many of the participants suggested that their parents, in particular, had established and nurtured a positive attitude in their daughters, empowering them and giving them a sense of self-worth. From the interviews, it became evident that the role of parents could be decisive in determining the outlook on life for a woman with disabilities and the kind of opportunities she had to develop her sense of self and sense of worth in terms of living with an impairment in a rural household.

4.3 Family and community as contrasting spheres

In comparison to the sense of acceptance and security that was described within the family and the closer circle of family and immediate community of close friends and relatives, the wider community was perceived with caution. Some of the mothers interviewed expressed a need to maintain constant supervision of their children and to confine them to the home. The wider community was perceived to be a sphere in which a woman with a disability would be vulnerable to sexual abuse because of her impairment, and potentially her children.

The lack of access for people with disabilities in wider society in general also operated as a barrier to participation. As discussed in section 4.10, some women have been able to address this barrier due to certain interventions that have empowered them.

4.4. Natural and built environment as a barrier

In each interview it was evident that disability was perceived to be due to a deviation from ‘the normal’ with respect to the physical, intellectual or the emotional. However, it was clear that the women experienced marginalisation, restrictions or discrimination due to the non-inclusivity of the natural and built environment. The lack of accessibility in Sri Lankan society has already been noted and critiqued. Lack of accessible transport and lack of access in the built environment, especially at public institutions and places of worship, were specifically identified in the interviews. The

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exclusivity of the media was also seen as an issue as it presented a barrier, especially for semi-literate people, to obtaining up-to-date information and/or entertainment.

4.5. Access to education, health care and employment

Access to education and health care was a challenge for the interviewees. In the rural context, they did not have access to facilities which enabled them to pursue their education without interruption. Transport to and from school and facilities for extra-curricular activities were lacking for most women. In certain cases education was interrupted due to receiving medical treatment for their disability. In one case, a woman was never enrolled in school due to her disability. The younger women and girls had had access to ‘special education’ in separate institutions for educating children with specific impairments. Those experiences were more positive and the interviewees expressed that there was a benefit to that education. The families were struggling, however, to meet the additional costs of accessing these institutions, even though the institutions themselves did not charge any fees.

Accessing the free-of-charge health-care services was also identified as a challenge. Many of the women had to travel long distances with the assistance of family members to obtain specific types of medical treatment that were available at specific hospitals only (for example, mental health clinics and medical care for children with Down’s syndrome). In one case, a woman had discontinued monthly visits to the mental health clinic as she was unable to afford the transport costs.

In the rural context, self-employment seems to be the primary type of employment for women with disabilities. Women were running small retail outlets or offering tailoring services, with assistance from AKASA, or were unemployed. Formal means of employment are limited in rural areas in Sri Lanka in general, and the absorption of people with disabilities in formal employment is significantly low. The running of small retail outlets by women with disabilities seems to be received positively in their communities, as described by the interviewees.

4.6. Gender, culture and disability

Against this backdrop, women with disabilities are subject to heightened discrimination because of the interstice of disability and gender. One such example, as was stated in the interviews, is the plight of women victims of sexual offences. Women in general find the criminal justice system far from conducive to investigation and prosecution of such complaints, independent of parochial cultural bias. The situation is further aggravated in the case of women with disabilities as the police

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24 For instance, it was established in a study that elderly women are more affected by health problems as opposed to men, due to their gender. See T Østbye, ‘Thirteen dimensions of health in elderly Sri Lankans: results from a national Sri Lanka aging survey’, 2009.
have almost no accessible facilities and neither do the courts. None of the women interviewed claimed to have been subject to sexual abuse, but they knew of or had heard of other women with impairments who had experienced such abuse. The interviewees stated that women with disabilities were reluctant to make formal complaints due to the belief that they would not be treated fairly. This issue is discussed in greater detail in section 4.7.

Women who had become disabled during the war stated that they had also experienced marginalisation as they did not fit in with cultural norms of womanhood, despite the fact that their impairment was a result of the long-standing 30-year conflict and not congenital. The research participants of Tamil background stated that in their experience, disability in the Tamil-Hindu culture and deviations from the ‘norm’ were considered to be bad luck. Acquiring an impairment appeared to reinforce such cultural perceptions surrounding disability.

Often, due to these cultural processes of stigmatisation and demonisation of disability, the research participants stated that they did not participate actively in significant community ceremonies such as weddings. The women with disabilities interviewed said they avoided attending these cultural community events either because of their impairment or because they were widowed (some women with disabilities interviewed for this study identified as ‘both’ categories). Some of the single women interviewed said they did not expect to marry due to their impairment, and therefore wished to avoid such cultural community events, even though they provided opportunities for socialisation and participation.

On the other hand, some women stated that due to the support of their spouses and due to their empowerment through AKASA training programmes, they had been able to overcome some of the cultural barriers they faced in their daily lives. This includes both everyday activities and formal cultural events such as weddings. Many of them considered their involvement with AKASA as a turning point in their life, and explained the difference in their outlook on life before and after their engagement with AKASA. Thus, additional gendered disability support, which conceptualised the interstice of disability and gender as an affirmative identity, provided a positive platform for the research participants to actively participate within their communities and be valued by these communities.

4.7. Criminal justice

The women interviewed were of the view that law enforcement agencies, judicial proceedings and the criminal justice system in general were not receptive to women with disabilities. The lack of facilities for people with disabilities in these public institutions, such as available interpreters, physical access and sanitation facilities, were pointed out. Especially in situations of violence against women with disabilities, the victim is disadvantaged and further victimised due to these factors. For instance, when a woman or girl with a speech impairment attempts to make a police complaint, in the absence of a translator she is compelled to humiliate herself by communicating through actions.
Where a woman with an intellectual disability is a victim of sexual violence, the long delays in the court process affect her ability to give accurate evidence before court.

It was also pointed out that there are no special facilities for people with disabilities in prisons. AKASA had been requested to admit juvenile convicts with disabilities to its vocational training institute because prisons were not equipped to accommodate them. AKASA had refused admission on the basis that convicts could not be accommodated with its other students.

A negative perception towards the police was evident among the women interviewed, who felt it was not a public institution that was sensitive to their concerns.

### 4.8. Law, policy, regulations and administrative discretion

The legal literacy of the women interviewed was poor. Due to their participation at AKASA training workshops, they were aware of a prohibition on discrimination based on disability. They were also aware that people with disabilities had a right to enjoy freedom of expression along with everyone else. Some were aware of the international Convention on the Rights of Persons with Disabilities. However, there was no knowledge of specific laws, or policies or regulations. Some interviewees were aware of some of the relevant regulations because of information they had received from AKASA.

There was no sense of a right to hold administrators accountable for the manner in which they exercised their discretion. Many of the relevant regulations vest administrators with discretion in regard to making certain forms of assistance available to people with disabilities. From the statements made during the interviews, it was clear that in many instances this discretion was exercised arbitrarily. No reasons had been given for decisions made. Furthermore, administrative procedures for approving loans, for instance, were cumbersome and time-consuming. In many cases a delay of several months or years occurred, with no clear justifications provided for such delay.

Bridging the gap between laws, policy and regulations on the one hand and the lived experiences of women with disabilities therefore emerged as a critical issue in the interviews.

### 4.9. Assistance from the state

There was a lack of clarity and understanding among the women interviewed as to the forms of financial assistance available to them from the state. As identified in the table in Appendix 3, there are numerous disability assistance programs covering key areas of social and economic life, including familial assistance for low-income households, housing assistance, medical care (including travel) and assistive devices, and employment assistance. Eligibility to these programs is generally restrictive, with either stringent income cut-offs, arbitrary reliance upon local government recommendations and/or medical certification of disability type and degree. Moreover, in reviewing
all these disability supports, none appear to be gender specific and seek to address issues of access, inclusion or participation unique to women with disabilities.

From the research participants, we were able to ascertain that in rural areas, the degree of support, if any, varied greatly for women with disabilities. For example, some women received a monthly grant, others had received a housing loan and some others had not received any form of assistance, nor were they aware of its availability. A few had applied for assistance and either had been refused (without justification) or been asked to wait for the application to be processed. The money being granted by the state as a general disability payment was incredibly low, Rs 300 (less than US$3) a month, and cannot be considered adequate.

Furthermore, the lack of uniformity in providing this monthly payment is discriminatory and problematic. According to the experiences shared during the interviews, the procedure to apply for this money is not a disability-friendly process. The women had to rely on a third party, such as a family member, to visit the relevant public officer, fill in the required forms and submit the required supporting documents. In many cases, AKASA had provided the required assistance to these women. Without this support from AKASA, many of the women with disabilities would not have been aware of, or accessed, a range of state assistance programs designed to support people with disabilities.

4.10. Social mobilisation on disability-related issues
Collective action for addressing issues faced by rural women with disabilities was discussed during the interviews as an extremely empowering experience. All the women who were interviewed were members of AKASA and had been involved in its awareness-raising programmes and training workshops. Through those events, they said, they had developed confidence and were made aware of their rights. It was also stated that only after joining AKASA had some of the women developed the confidence to travel on their own, assert themselves and live with a sense of self-worth. It was evident that the leadership of AKASA had been inspirational to the women who were interviewed.

These experiences strongly suggest that social mobilisation and collective action within the community of people with disabilities is essential to address disability-related issues. The specific example of AKASA, however, suggests that access to political power and patronage effectively determines the success of such collective action and social mobilisation. Whether it is to access information, establish an organisation, seek funds/assistance from the state or introduce change, it seems that access to political power/patronage is essential.

4.11. Relevance of political power and patronage
The work of AKASA and its achievements were described in the different interviews that were conducted across the diverse group of women. In fact, women with disabilities from either a Sinhala or Tamil or Muslim background all confirmed that it was due to AKASA’s social programming and
advocacy that they were able to seek greater access to services, supports and development programs.

It was evident from those responses that AKASA had purposefully maintained links with successive governments and worked closely with them on issues for women with disabilities. At present the organisation has direct access to the President of Sri Lanka and has therefore been able to bring about significant changes in state practice to meet the needs of people with disabilities. AKASA was granted land by the state when the institution was set up in Anuradhapura and the organisation has continued to enjoy the patronage of political parties in power, which in turn has given AKASA access to the bureaucracy.

As an example of the benefits of this access, AKASA has compiled administrative regulations relevant to people with disabilities. Accessing these regulations is generally difficult as they are not made freely available to the public. But because of the political connections that AKASA maintains, it was possible for its leadership to access these documents.

The experience of AKASA strongly suggests that political support and involvement is essential to the success of collective action or social mobilisation aimed at addressing the needs of people with disabilities, and in particular, rural women with disabilities.

4.12. Disability due to internal armed conflict: gendered dimensions

Research suggests that armed conflict has a particularly adverse impact on women and that social support is necessary in addressing the post-traumatic stress experienced by women affected by conflict. It could be argued that women who had become disabled due to the armed conflict are much more vulnerable to post-traumatic stress. The interviews conducted in the Batticaloa district were with women who had become disabled during the conflict, either as combatants or as civilians caught up in the fighting. Some were adults and some were children when they became disabled. Apart from having to cope with their impairment in an inaccessible environment that did not facilitate disability inclusion and participation, these women continued to care for their families in their roles as home-makers. In one case, a woman had been widowed because of the war and in two other cases the spouses had also become disabled. Consequently, the full responsibility of household care for children and other family members, alongside providing economically for the household, fell on these women.

Non-governmental organisations played a significant role during the armed conflict in providing appropriate care, rehabilitation and assistance to women with disabilities. The women with disabilities interviewed for this study stated that the LTTE or the Karuna faction of the LTTE provided specific facilities for those who had become disabled due to the armed conflict, even if

they had been combatants. Even during the armed conflict, these women were able to receive necessary medical treatment from the state-run hospitals, including at the national hospital in Colombo. None of the women interviewed identified discrimination due to their ethnicity in those situations.

4.13. Bridging differences between communities through community-based action around disability

The Sinhala and Tamil women who were interviewed stated that being a member of AKASA had given them an opportunity to work closely with people of the other ethnicity. As a result, they were able to overcome their suspicion and fear of the ‘other’ ethnic community. For instance, a woman from the Batticaloa district said that prior to her involvement with AKASA she had not travelled on her own to a Sinhala area, but travelling to Anuradhapura to attend AKASA meetings had helped her overcome her fear about being on her own in a predominantly Sinhala environment. A Sinhala woman stated that meeting Tamil women with disabilities through AKASA had helped her understand the problems they faced and helped her see beyond the stereotype of Tamils as ‘terrorists’.

The researcher could observe that the women had built close relationships across the ethnic divide. The mutual exchange of good will had improved their willingness to communicate with each other and to work together for the benefit of women with disabilities.

05. Conclusion

This report details the central themes to emerge from a small research project that aimed to investigate, document and understand the lived experiences of women with disabilities residing in rural Sri Lanka in a context of post-armed conflict. A key finding from the report highlights that for rural women with disabilities across all ethnic dimensions, an elevated social status, arising from access to political power/patronage or economic power, can reduce the marginalisation that she would otherwise experience.

The interstice of gender and disability and rurality created a number of acute disadvantages that would not be experienced by women with disabilities residing in urban areas. This was most evident within the realm of access to reliable and up-to-date information on state disability supports and programs that would increase the research participants’ social and economic wellbeing, and their effective participation in health, education and cultural systems.

For rural women with disabilities, issues related to distance have a critical impact on all parts of their lives. Distance was strongly associated with the non-availability of accessible and affordable public transport to support travel to regional state welfare offices which provide disability support in some form. Nearly all the women with disabilities interviewed for this preliminary study did not
know about, nor could they have access to, the available government fiscal and program support as the distance between ‘home’ and ‘the state regional office’ was extremely difficult to negotiate. Information about disability supports and programs was not available in rural locations, and women with disabilities were unable to access this information as their travel was impeded by the lack of transport systems.

Rural isolation therefore significantly heightened their exposure to abject poverty and, in turn, access to medical, education, economic and social support systems that are critical for both sustaining individual wellbeing, and actively supporting rural women with disabilities’ engagement within their local communities, economies and cultural life. This situation was heightened for those women with disabilities residing in rural areas who were the primary carers of partners/husbands, children and other household members, as they were the central informant on available state supports and services for the entire household.

Living rurally also created a number of additional vulnerabilities for women with disabilities, as in many instances they had to rely upon the goodwill of an informal network of individuals, including strangers, to access very basic supports. In terms of access to state assistance, this was particularly acute as many of the women were forced to ask others to complete and submit key sets of information on their behalf. These sets of information were then used by public officials to determine eligibility to state fiscal and programmatic supports. Thus, if the women were unable to advocate for their own needs, they risked being misrepresented and, in turn, losing potential access to vital disability supports to sustain their individual and household wellbeing.

The interstice of rurality, gender and disability therefore creates a number of vulnerabilities and insecurities for women with disabilities. These heightened insecurities were only addressed by the specific gendered-disability advocacy and support offered by AKASA, Sri Lanka’s only group for rural women with disabilities. Advocacy for the specific needs of women with disabilities residing in rural environments enhanced the overall material, social, economic and cultural wellbeing of the women. In nearly all instances, the rural disabled women participants identified the essential role of disability advocates who also had a strong awareness of, and commitment to, women’s empowerment. AKASA’s ethical mandate to advocate specifically on issues of direct relevance to rural disabled women had a positive impact upon the women’s individual lives and, consequently, on the households in which many of these women provided care as partners/wives, mothers, in-laws and so forth. This impact was felt economically, as the additional disability support contributed to alleviating conditions of abject poverty in the household, and socio-culturally, as the women both themselves and with support from their household network actively engaged in their communities and participated in local cultural events.

Even though AKASA works within a gendered, disability rights paradigm to underpin its services, programs and advocacy support, there was minimal awareness among the participants of the
concept of rights, let alone the concept of rights for people with disabilities, or the common idea of disability rights. Yet, many of the women were of the view that they were respected by their family and that their dignity was recognised. This feeling did not extend outside the home, however, as illustrated by the research participants’ views about access to public places, such as religious institutions, and access to education.

In reviewing the individual interviews and the focus group discussions, there was no evidence to suggest that the women with disabilities interviewed for this study had been able to make progress in their lives using the notion of rights. This should not be surprising given the limited awareness of rights generally. Yet, any sense of having rights seemed to have led to a sense of self-worth. Thus, however limited, an awareness of rights had a positive effect at the individual level, but opportunities for the women to advance disability rights within public spaces and places was constrained.

It was pointed out by one of the leaders in AKASA that referring to the concept of human rights, in some cases, led to an entitlement mentality and that it problematised disability in an unprecedented manner. What had been normalised was now destabilised and it was felt that this led to disruption within communities around perceptions and engagement with women with disabilities. In a context where disability was not yet considered an affirmative ‘identity’, the researcher observed that offering human rights as a framework to address issues related to disability was not particularly useful. It could potentially also be damaging, in that the very act of posing questions regarding the rights of people with disabilities could destabilise the sense of harmony that some of these women had struck in their private households to maintain their wellbeing and the wellbeing of those that they cared for. Unless there is a political, legal and social context within which the concept of human rights for people with disabilities can be implemented, it is not clear how relevant this discourse may be to women with disabilities in rural areas.

Finally, the non-identification of rights as a central component to advancing the social, economic and cultural participation of research participants may be associated with the fact that the Sri Lankan government, at the time of the interviews and writing of this report, remained signatory only to the main body of the CRPD. Given this broader socio-political context, there has been no international obligation upon the Sri Lankan government to advance disability rights as a public policy area of reform. The unique inclusion of gender-specific provisions alongside Article 6 of the convention, Women with disabilities, provides a legal, social and cultural framework in which to advance the inclusion, participation and engagement of rural women with disabilities. Thus, we strongly urge the Sri Lankan government to ratify, as early as possible, both the main body and the optional protocol of the CRPD. This would then initiate a range of policies, processes and strategies that would directly benefit the rural women with disabilities who participated in this study.
References


http://dx.doi.org/10.1080/01436597.2011.604518


Constitutions
Constitution of Sri Lanka 1978

Legislation
Mental Diseases Act No 27 of 1956
Rana Viru Seva Authority Act No 54 of 1999
Election (Special Provisions) Act No 28 of 2011
Protection of Rights of Persons with Disability Act No 28 of 1996

Case law
Ajith Perera v Attorney General SC (FR) 221/2009, SC Minutes of 27 April 2009
Appendix 1

THE UNIVERSITY OF NEW SOUTH WALES AND THE SOCIAL SCIENTISTS’ ASSOCIATION

DISABILITY RESEARCH PROJECT
Rural Disabled Women’s Social Inclusion in Post-War Sri Lanka
HREC: HC 14052

What is this study about?
This study is about understanding the life of women with disabilities in rural areas of Sri Lanka. The study is to help us understand your day-to-day experiences of social inclusion in your local community, especially now that the war has ended. We hope that this will help us to understand what supports women with disabilities in rural areas of Sri Lanka need to be actively included in their communities as equal community members.

Who can take part?
You can take part if:
- If you are a women with a disability aged between 18–60 years;
- If you live in a rural area of Sri Lanka; and
- If you are involved in some kind of social support program.

Who is doing the study and why?
This study is being undertaken at the School of Social Sciences, UNSW Australia and the Social Science Association of Sri Lanka. We are also working with AKASA, the local rural women with disabilities advocacy service. We are working together so that we can contribute to understanding the lives of rural women with disabilities in Sri Lanka, so that hopefully, it can be improved.

If I decide to take part, what will I need to do?
First, let your disability worker with AKASA know that you are interested. Your disability support worker will then let us know that you are interested. We will then contact you and ask if you would prefer to be alone when you meet with us, or if you would like to be in a group.

If you want to be interviewed by yourself, this will take about 1 hour.

If you want to be in a group it will take about 2–3 hours. The focus groups will take place at the AKASA offices closest to your house. We will organise your travel to and from the AKASA offices for the focus group.
What will the information be used for?
The information will be used for books, talks and papers that researchers read. We will also write up information for AKASA to go out in their newsletter so that you can read about what we found.

What happens to my information? Will it be confidential?
The information about you will be confidential and will be locked in a room that only the researchers can access.
Your name and any information about you that can identify you will not be shared with anyone – this includes your disability support worker, family members and other community members.

This means the researchers:
• Don’t use your name
• Don’t use the name of the town where you live or the names of other towns close by
• Make sure any pictures or writing that you may want to do don’t show who you are

Is the participation voluntary?
Participation is voluntary and can be revoked at any time without consequences. Participation and revocation have no impact on any services participants receive from AKASA and will have no impact on any relationship with UNSW.

The choices that you can make include:
Choose to be interviewed by yourself;
Choose to be recorded or not by the researcher
Choose to participate in a focus group.

You can choose to leave the study at any time you are involved.

What if taking part is upsetting?
Participants can speak to the researcher and ask for a referral to be made to a disability advocate or a staff member of AKASA. You can choose to leave the study at any time, including during the interview or in the focus group.

What if I have complaints about the study?
If you have complaints about the study you can contact Dinesha Samararatne on email on: dinesha@law.cmb.ac.lk or phone: 077 301 5252

What if I have more questions?
If you have any more questions, feel free to contact one Dinesha, the field researcher, who will be happy to answer them in the first instance. You can also contact Karen, the Australian researcher if you think that this is better for your questions. Karen’s email address is: k.soldatic@unsw.edu.au
I WANT TO TAKE PART

I am signing this form because I understand the study.

I want to take part in:

☐ An interview between me and the researcher;

☐ A focus group with me, other women with disabilities and the researcher.

☐ I agree to let the researcher record the interview.

.................................................. ..................................................
Signature of Research Participant Signature of Witness

..................................................
(Please PRINT name)

..................................................
(Please PRINT name)

..................................................
Date

..................................................
Nature of Witness
PARTICIPANT CONSENT STATEMENT

Rural Disabled Women’s Social Inclusion in Post-War Sri Lanka
HREC: HC 14052

I DON’T WANT TO TAKE PART ANYMORE

I am signing this form because I don’t want to take part anymore in this study.

I don’t want my information to be used that I have given you.

........................................................................................................................................
Signature Date

........................................................................................................................................
Please PRINT Name

The section for Revocation of Consent should be forwarded to Karen Soldatic, School of Social Sciences, University of New South Wales, Kensington, NSW 2031. Email: k.soldatic@unsw.edu.au.
Appendix 2

Financial assistance from the state available for people with disabilities

<table>
<thead>
<tr>
<th>Type of financial assistance</th>
<th>Amount</th>
<th>Main requirements in application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing assistance</td>
<td>250000</td>
<td>The applicant should own a piece of land. A certified copy of the deed must be submitted</td>
</tr>
<tr>
<td></td>
<td>1925</td>
<td>Monthly income should be below Rs6000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age limit is 18-70 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>An estimate has to be submitted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All the above documents and a completed application along with the recommendation of Divisional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Secretary has to be submitted</td>
</tr>
<tr>
<td>Medical assistance</td>
<td>20000</td>
<td>Cost for treatment/surgery</td>
</tr>
<tr>
<td></td>
<td>154</td>
<td>Medical certificates</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A letter of recommendation by Divisional Secretary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A letter of request for financial assistance</td>
</tr>
<tr>
<td>Assistive devices</td>
<td>25000</td>
<td>Recommendation of the Secretary of Local Authority (<code>Pradeshiya Sabha</code>)</td>
</tr>
<tr>
<td></td>
<td>192.5</td>
<td>Recommendation of the village-level administrator (<code>Grama Niladari</code>)</td>
</tr>
<tr>
<td></td>
<td>10000</td>
<td>Prescriptions for spectacles and eye lenses have to be submitted</td>
</tr>
<tr>
<td></td>
<td>77</td>
<td>A recommendation letter from Divisional Secretary has to be submitted</td>
</tr>
<tr>
<td>Self-employment assistance</td>
<td>25000</td>
<td>The applicant’s monthly income should be below Rs6000</td>
</tr>
<tr>
<td></td>
<td>192.5</td>
<td>An estimate for the self-employment should be submitted</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The completed application and estimate have to be sent along with the Divisional Secretary’s</td>
</tr>
<tr>
<td></td>
<td></td>
<td>recommendation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medical Certificate</td>
</tr>
<tr>
<td>Payment of a sum of Rs3000 for the family</td>
<td>3000</td>
<td>Families with low income level (below Rs3000/month)</td>
</tr>
<tr>
<td></td>
<td>23.1</td>
<td>Number of persons with disability in the family is considered for the selection of recipients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Priority is given if the breadwinner has a disability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If the person is severely disabled, priority is given</td>
</tr>
<tr>
<td>To purchase medicine and travel expenses</td>
<td>20000</td>
<td>A prescription of medicine to be purchased has to be submitted (certified by the medical officer)</td>
</tr>
<tr>
<td></td>
<td>154</td>
<td>An estimate for the medicine from Osusala (state-run pharmaceutical chain) has to be submitted</td>
</tr>
</tbody>
</table>

Note: Rs1 = US$0.0077