Article 19 Project Briefing to:

Members of Parliament

21 January 2013
About us

CCS Disability Action is one of the largest disability services providers in New Zealand. We have been advocating for disabled people since 1935. Today, our organisation has a strong disabled leadership and human rights focus.

CCS Disability Action has a National Office and regional management structure, and provides services nationally from sixteen incorporated societies. We deliver services to over 6,000 disabled people of all ages, their family and whanau. We also administer the Mobility Parking Scheme for over 100,000 people.

The Article 19 Project: When every voice is heard - Finding a place for the life stories of disabled people who have high and complex support needs.

In 2011 CCS Disability Action commissioned the Donald Beasley Institute to conduct a research project (named the Article 19 project) into the lived experiences of disabled people who have high and complex needs, specifically on the right to live in the community, with choices equal to others, and the right to full inclusion and participation in the community expressed by Article 19 of the United Nations Convention on the Rights of Disabled Persons.

The United Nations Convention on the Rights of Disabled Persons (UNCRPD) is the latest in a sequence of conventions that recognises particular categories of humanity as worthy of specific human rights protection.

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**Article 19 - Living independently and being included in the community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

A. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

B. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

C. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.
The Multi Region Ethics Committee granted ethical approval for the CCS Disability Action / Donald Beasley Institute Article 19 project on 16 March 2011 and CCS Disability Action distributed participant information and interest forms to disabled people to begin the process of project recruitment.

Potential participants responded to the invitation and to ensure that everybody had an opportunity to take part in the Article 19 project the final selection of participants was made by the Donald Beasley Institute research team on 27 May 2011.

Seven male and five female participants were chosen using a maximum variation sampling strategy. Participant’s ages ranged from 23 – 54 years. One participant self identified as Maori. All but two participants described themselves as having more than one type of impairment. Eleven self reported a physical impairment, seven reported a sensory impairment, seven an intellectual impairment and one self-injurious behaviour. Selected participants also varied in their living circumstance, including: living at home with parents who were actively engaged in their support (4), living in a ‘granny flat’ on with individualised funding (1) and contract board (1), receiving support in a residential facility with 2-6 other service users (3), flatting by themselves with personal and vocational support (2), flatting with a chosen flatmate and receiving personal and vocational support (1) The majority of participants also named at least one other person to inform their narrative.

The objective of the Article 19 project was to attempt to provide twelve disabled people with high and complex support needs the opportunity to tell their own story, their own way. The methodology used to further this aim is described in detail in the Article 19 project but in short, a mixed method approach was employed and proved especially effective. Data was managed using statistical software with data sets created for information generated by the Time in Place Diary, Quality of Life Questionnaire and Friendship Field maps.

The key themes to emerge from the Article 19 project with regard to the three specific components of Article 19 of the UNCRPD include, but are not limited to, the following:

**Choice of residence** : Article 19 (a) of the UNCRPD states that ‘Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement ‘

The twelve narratives that informed the Article 19 project told a story of adult New Zealanders whose lives had not followed the normal transition to adult life beyond the family and parental home. Participants did not describe the same rights of passage as those experienced by their non-disabled peers.
The vast majority of participants (11) did not expect to own their own home and all felt constrained by the limited range of service options available to them.

The narratives that informed the Article 19 project indicated that the majority of participants did not feel that they had the right to ‘choose their place of residence and where and with whom they lived’.

The Article 19 narratives detail the difficulties that six participants, their families and whanau experienced finding alternatives to the standard model of residential care.

Home for six of the twelve participants who contributed their stories to the Article 19 project either lived with parents in the family home (5) or a home created by a family that had absorbed them (1). All six had remained at the family home for different reasons but the unifying theme to their narrative was of the great difficulty people perceived in finding services that replicated the quality of life experienced within the sphere of familial love and aspiration.

Three of the participants who identified as requiring behaviour support continued to live in the family home. The families of two of these participants had explored and rejected residential / group homes (deeming them to be inappropriate places for their family member) and the options were limited for the third participant for whom an aged care provider appeared to be the only service prepared to accommodate their son.

The three participants who resided in residential facilities spoke about their inability to choose who they resided with. Two of these participants talked about having no choice but to live in a residential facility concluding that this was due to their need for high levels of support. One participant said that she would like to live in a home of her own but believed that the government would never fund a living arrangement that would keep her safe in a home of her own.

Participants who lived by themselves or with a chosen flat mate (3 participants) prioritised the importance of ‘home’ often at the expense of support that enabled them to access and participate in their community with access to support services being limited and constrained.

**Access to home and community support services:** Article 19 (b) of the UNCRPD states that ‘Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’

The twelve narratives that informed the Article 19 project indicate that participants did not enjoy access to the support and structures necessary to live in and to participate in their community and in society as equal citizens.
The lack of choice with regards to accommodation options as detailed above and the physical inaccessibility of community housing stock limited the participant's access to the private social spaces enjoyed by non disabled New Zealanders.

The narratives that informed the Article 19 project indicate that support services are largely inflexible and out of beat with the ordinary rhythms of home and community life, that participants who relied on non conventional expressive communication had limited access to communication aids and technology, that support hours (especially for people in receipt of supported living /supported independent living) was limited and defined the narrow range of activities and opportunities to participants.

Participants who lived by themselves or with a chosen flat mate (3) prioritised the importance of ‘home’ often at the expense of support that enabled them to access and participate in their community.

Families that continued to support their son or daughter in the family home spoke of limited resources and of the families' orientation towards meeting the support needs of their disabled staff member and of the demands on their time.

No one other than support staff visited the houses of those participants who lived in a residential setting. This group experienced segregation and very limited access to the resources to make the community accessible.

There was no transparent relationship between participants allocated support hours and their lived experience of disability and /or absence from community and social relationships.

**Equal access to community services and facilities:** Article 19(c) of the UNCRPD states that. 'Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs'.

The segregation and absence of the 12 participants from their community was evident through out the research. Most participants identified poverty, a range of environmental barriers, limited support hours, lack of access to augmentative and assistive communication technology and a siloes approach to service provision as barriers to inclusion.

Absence from the worlds of employment and education meant that none of the research participants named as a friend anyone drawn from these ordinary participatory contexts so often the source of social relationships and friendships

Most people who participated in the Article 19 project were absent from those environments and settings where non disabled people so often derive a sense of participatory citizenship. Not having a presence in the world of employment, education or inclusive sporting, recreational, creative, cultural, political
environments and activities denied participants access to the valued social roles of workmates, colleagues, peers, friends, neighbours and citizens

Beyond the relationship that had developed with staff, none of the participants included in their friendship field anyone that they had met through their vocational service even where the service purported to be individualised rather than centre based.

**Summary**

 Whilst the Article 19 project research is yet to be released to an external audience we felt it only right to brief the Minister prior to its release.

We respect and honour the work of the Minister to promote and protect the rights of disabled people, their families and whanau and believe that the 12 narratives that inform the Article19 project will contribute greatly to reflection about how best to acknowledge the right of people with high and complex support needs to live in their communities with choices equal to others and to establish a clear action plan for the implementation of the reform necessary to ensure compliance with Article 19 of the UNCRPD.

Being present in the spaces in which “community” is transacted is central to our understanding of citizenship. Although people with high and complex support needs have been described as the last to experience the benefits of socio-political and disability related service change, the voices of those at greatest risk of marginalisation are yet to find their place within the disability or social justice discourses.

An assessment of the progress being made towards recognising the right of disabled persons to live in the community with choices equal to others is not possible without including the experiences and perspectives of citizens at greatest risk of exclusion. This topic is important because it seeks to co-produce the prerequisite social knowledge with disabled people whose rights are most likely to be infringed.

CCS Disability Action and the research team at the Donald Beasley Institute are monitoring the Inclusion International’s campaign to promote Article 19 of the Convention for people with intellectual disabilities. As part of their data gathering strategy, Inclusion International have invited the international research community to submit relevant research findings and CCS Disability Action is well placed to disseminate the Article 19 project findings to an international audience.

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