# Disability

## A Pacific experience

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**ABSTRACT**
This paper is a personal perspective about the disability issues within the Cook Islands. It looks at how the needs of children and adults with disabilities have been addressed over the years and the vision of many people who have worked towards building an inclusive society, starting with mainstreaming in the schools to full inclusion. It discusses the challenges along the way and the challenges that continue. This paper hopes to convey a message to all readers which promotes inclusion in the Cook Islands, and that with inclusion a strong base can be developed in all individuals about acceptance and understanding of one another's needs. To achieve this, one needs to be exposed to people's differences and to value people's differences. However, for this to be successful, the appropriate supports need to be in place and it is vital that all work towards the same vision.

**Storied experience**

**Keywords**
*Competence, cultural differences, Pasifika children, professional training, special needs, teacher development*

### INTRODUCTION

Paradise! That's where I live, blue oceans, white sandy beaches and generally lots of sunshine. Oh yeah, did I mention the wonderful sunrises and sunsets? Absolutely fantastic! Yes, the Cook Islands are definitely a "heaven on earth" and a wonderful place to live because the people are beautiful and they are caring. I know this to be true as I work with people with disabilities in the Cook Islands and have seen the love and devotion shown. However, I have also seen the struggles and frustration by many family members and caregivers dealing with supporting their loved ones who were born with a disability; struggling to care for these people with limited support and understanding of these issues on the island. Family members often feel quite isolated having to solve the caregiving problems by themselves. The same holds true for individuals who have obtained a disability due to accidents or traumas. Family members have to deal with the changes that saw their loved ones living independently, and then becoming quite dependent on them for their daily activities. If the families and caregivers struggle, then one must think about what the individual with the disability is experiencing and how this affects them personally.

Until recently, people with disabilities and their families received little or no support in the Cook Islands. In the past, the only available service was a small disability pension provided by the government, and the Cook Island Disabled Persons Centre organised by volunteers catering for all children/adults with disabilities. There were some excellent programmes within this centre that had been put in place over the years. However, the programmes didn't last and prior to my return to the Cook Islands 9 years ago, the adult programme had not been in operation for at least 7 years. A satellite classroom had begun in a mainstream school for the children. Within the community, there appeared to be a mind set that improvement in an individual's abilities is limited with a common belief that generally people with disabilities do not have much potential for learning or change. Therefore, until recently, our children with disabilities were kept at home. How can a population of people accept or understand people with disabilities if they do not see them out and about in their community, being a part of the community's ebb and flow? Similarly, how can families or caregivers lobby for support when most do not actually think that there is any need, because the attitude is one of "what can be done at the end of the day"? From my perspective, there seems to be little understanding and awareness in most Cook Islands families who have loved ones with disabilities which potentially means there is generally less of the same in the larger community.

### CHALLENGES ALONG THE WAY

Over the years, many successful programmes have been put into place based out of the disability centre. Programmes included life skills, vocation/prevocational, preschool and school age. These programmes were run at different times throughout the day catering for the different age groups. I remember working as an assistant in the very early stages of one of these programmes and was overwhelmed by the amount of work that was carried out by the coordinator, who was a New Zealand-trained occupational therapist. She did it all as there was no one else trained in the area, but she had great support from the committee at the time that was the driving force behind this programme. Unfortunately these programmes have not continued over the years; sustainability being a real issue.

Sustainability is probably one of the most important areas to address when looking at establishing and providing programmes and services. This is particularly so in the initial stages, as it is important that services remain not only constant, but also reliable. In my opinion, stable service delivery means that those with disabilities are more likely to achieve their goals. Much of the work carried out with people with disabilities has been organised or developed by volunteers, both Cook Islanders and people from overseas, who were relied on heavily to continue this work. This may

be one of the reasons why programmes did not survive as it was a huge commitment to expect of a volunteer.

Our committees are made up of volunteers, most holding down their regular jobs throughout the day, meeting to manage the programmes after work hours. These committee members are generally the people who find the funding, employ the staff and oversee the whole programme. It is this committee that would have first identified the need for a particular service, so the initial set up would have been required, and then the continual follow up. Our minimum wage here is $5.00 an hour (it was a lot lower years ago), so to find staff that were trained in this area and competent would be challenging in itself. The committees also change membership every two years during the annual general meetings, which gives others the opportunity to be voted on the committee, and some voted off. Changes in committees can sometimes mean changes in vision which can be either positive or not!

An example of a programme reliant on volunteer contributions was that of a satellite school, with the idea being first suggested in the mid 1990s. This was a wonderful forward thinking concept for a small country, bearing in mind that our population at that time was 18,000 people. The proposal involved placing a satellite classroom within one of our local primary schools, the intention being to mainstream children into the regular school, supported by a team of one teacher and volunteers. Although a wonderful plan, I believe, the team was too advanced for the rest of the country at the time, and received minimal financial support from the mainstream education system. Therefore this group of dedicated people had to rely primarily on fundraising and donations to support their programme. When I think about the ideas and plans they had put into place at the time, one must really admire the efforts, the outcomes they achieved, and appreciate the challenges that were experienced. Given the nature of disability is broad, it was not uncommon to have a range of children in the programme including those who were deaf, had severe multiple disabilities, learning difficulties, or a physical difficulty. Whilst some of our local teachers were sent to New Zealand or Fiji to be trained, it was a big ask of staff to be expected to work with the broad range of disabilities with minimal external support.

## WHAT IS HAPPENING NOW?

Today, the Ministry of Education is fully onboard and the Cook Islands are fully inclusive with all students attending the mainstream schools. The change from volunteer-managed programmes to what currently happens began by the Ministry of Education employing a special needs adviser, with one of the main goals to develop the special needs policy. A private school had already taken the initiative and had three children with special needs enrolled at their school, and privately funded a teacher aide (who was a qualified occupational therapist) who worked one-to-one with these children. This school (Te Uki Ou[1]) took the lead in mainstreaming, continuing to expand by enrolling children who had cerebral palsy with quite high needs. At the time there was no formal funding for teacher aides, so volunteers were used which included parents and Global Volunteers (an American organisation who regularly sends volunteers to the Cook Islands). The school relied heavily on Global Volunteers for the first two years who worked with the children in wheelchairs, with volunteer parents providing the continuity of services between one team leaving and the next arriving.

This initiative of mainstreaming was driven by the first principal of Te Uki Ou School, and progressed down through her team of teachers who were all dedicated to teaching "all children". The school privately funded a special needs teacher to work with children who required extra supports, as well as at a later point privately funding teacher aides for the student. The new principal who took over the management of the school, along with her husband, personally built the ramps into the classroom and around the school to enable better access for the children. Initially all required resources and supports for the children with special needs were received as donations, including a separate building for individual lessons or personal care as appropriate. Our Cook Island Red Cross Society was given a van by Rotary, and they transported our children to school daily, relying on donations to fund the petrol costs.

From this early start in just one school, we now have teacher aides for most of our children with special needs throughout the whole of the Cook Islands, with teaching hours being applicable to the child's needs, plus teacher aides who are also assisting with Reading Recovery programmes. We have one high school that has a satellite classroom (which was donated) and a special needs teacher who oversees the programmes of the children in this school. There is another learning resource teacher at our National College with a special needs adviser who oversees the whole of the Cook Islands. These services are now all funded by the Ministry of Education. New Zealand AID (NZAID) has played a large part in assisting the Cook Islands with developing special needs and inclusive education within this country. NZAID funding contributed towards employing teacher aides, specialist training, specialist teachers and resources. Without this support from and partnership with our Ministry of Education, this degree of progress would not be evident today.

One issue that continues to arise is that of stability of teachers and support staff. The Cook Islands is a transient country with a reasonably high turnover of teachers; movement of staff can result in differing ideas predominating as new staff enter the programmes. Not all staff are for inclusion as some teachers feel it means more work. Again, this is an understandable response as teachers are expected to do much nowadays, however, if our teachers don't teach all our children, what will happen to our children who have extra needs? Are they to move back into segregated schools where yes, they could probably make good improvements in some areas IF we had the qualified people to work with them, but what about socially? What about emotionally? What about the opportunity for all children to learn and accept each other's differences? Most importantly, what about what the child or the parents want? We really need to ask ourselves these questions and come up with an answer that is encompassing these children's needs, and not just our own, and find that balance and compromise to fulfil both.

[1] Informed consent has been obtained from Te Uki Ou School management to share this storied experience.

We also have to ask, when did we start to differentiate between our children in terms of those who should be taught, and who shouldn't be taught? I guess that is why we have equal rights laws now, stating "equal rights for all". These laws we must all, worldwide, advocate for strongly. Nonetheless, our education system here in the Cook Islands needs to be congratulated in regards to the work that has been achieved for our children with special education needs so far. We have an existing special needs education policy which was drafted and implemented in February 2002. Currently there is a move underway to review and refine the policy into an inclusive education policy that both reflects a wider meaning of inclusivity and will also guide the process of bringing about changes, through school-level action. All our primary and high schools are officially mainstreamed. The Ministry of Education has provided us with teacher aides and learning support teachers. Our Cook Island teachers training college also has an inclusive education component, with graduate teachers coming out into the workplace with an understanding of how to work as an inclusive teacher. Unfortunately our training college has closed down this year, as there is no need to train more teachers although it is hoped that this is only temporary. Sure, there are many teething problems, as is to be expected with any new initiative, and ongoing training and education and support is still required for our teachers, teacher aides, and staff, as well as the parents. But it is the first step.

## WHERE TO NEXT?

To achieve a successful inclusive society, we must start within the school and all within the system must support. Support must start with the head of the ministry, through to principals and the teachers. I have found that it can just take one person to not fulfil their responsibilities for inclusion for a child to totally "miss out" on the "normal" experiences of an average person, that of an education and the opportunity to socialise with their peers. Our community also has an important part to play as it needs to embrace the inclusive concept for this to be successful, ensuring the environmental and social opportunities are accessible to everyone. It would be a shame to see the hard work that has been achieved by all those dedicated people from the past, whose vision was to see equality within our schools and the community, lost in return to segregation and isolation. As a teacher, a parent, or a member of society, it is our job to develop our children's knowledge base. What better way to start than by promoting inclusiveness, socialisation, understanding, and acceptance of each other for who they are and what they stand for, regardless of our personal belief systems. However, for inclusion to be realised within the schools, and then follow on into the community, more understanding is essential. It is great having teacher aides in the schools, but are they well trained to work with the children? Are the teachers supporting the teacher aides? Who is supporting our teachers and do they have a solid understanding of working with children with varying needs? Do they want to work with these children? Do our children within the schools understand the difficulties some of our children have? Have the children at the school received education toward increasing their understanding and awareness? Are the parents actively involved in the child's programme planning? Do our children have Individual Educational Plans? Are our children learning or are they just sitting in the classrooms? All these questions need to be addressed and with one inclusive educational adviser to oversee the whole initiative, we can quite confidently say there is still a lot more work required to ensure this is successful. It has only been six years since our inclusive education policy was introduced, so we are still very new and much more needs to happen.

## INCLUSION

### A case study

Inclusiveness offers opportunities for individuals to develop and strengthen their personalities and character by learning from each other and imitating their peers. If surrounded by a supportive environment, both human and non-human, the individual gains confidence and self-esteem and generally feels good about themselves. I have found that our people here who have a disability generally do not have a "voice" and that decisions are often made for them. The actual task of thinking for oneself or making their own choices is not something that is commonly done. When an opportunity does eventually arise to do something that is possibly community focused, many barriers begin to emerge as the individual doesn't know how to socialise with others well, or how to behave in an appropriate manner. Some individuals with disabilities have been brave enough to ask that they be considered a "normal" not disabled person. With this belief, the individual may not want to be involved in any activity connected with being labelled disabled. They appear to want to disassociate themselves from being labelled disabled. Let me illustrate these points with the case study of Ina[2].

### Ina

I once worked with a wonderful young man named Ina. Ina is 21 years old now, and was in an accident when he was 8 years old. He was sent to New Zealand straight after his accident, then returned to Rarotonga a year later. However, he never returned to school as, at the time, accepting children with disabilities within the mainstream system was not common practice.

Ina's family were loving and caring and supported him well, and he had good family contact and socialisation. He was pretty much the centre of their environment, being raised well-protected and loved. However, as he got older his personal needs changed and he eventually attended the Creative Centre[3], a programme for adults with disabilities. It was here that Ina began to experience life in a broader sense. He had a staff member who worked individually with him to help him achieve his personal goals. Although he was not totally comfortable being in a place for people with disabilities, Ina appreciated what they offered and the support he received.

This programme gave Ina many opportunities that he had not previously had, and it was the first step into a bigger social environment, even though it was disability orientated. A goal he had worked hard to achieve unfortunately did

[2] Informed consent has been obtained from Ina and his family to use Ina's name and tell his story.

[3] Informed consent has been obtained from the Creative Centre management to share this storied experience.

not eventuate, and our Disability Action Team (a technical assistance initiative funded by NZAID to support the implementation of the national disability policy) was approached to see if we could assist in any way to alleviate some of the disappointment he felt. It just so happened that at that particular time I was taking a team away to compete in an international sporting competition. After some discussion with Ina and the staff from the Creative Centre, Ina reset his goals and it was decided that he would travel away with us to compete in a sport he had not previously tried. We had a month to train him. As I was travelling with a youth team, the ages of Ina and the team weren't that far apart. The staff member who worked alongside this young man at the Creative Centre was also recruited to work with us to help maintain some form of continuity and support for Ina.

Overall, this trip gave Ina a new perspective on his life, because he mixed well with the rest of his team mates, trained hard, and gained so much from being accepted as a member of the team, rather than the guy with the disability. On our return, he was adamant that he wasn't going to return to the disability programme, and wanted to get employment. I believe this shows a very positive outcome of the work the disability programme at the Creative Centre achieved, as they prepared this young man for the life within the community, and now, that's where he wants to stay which reinforces the aim of inclusion by the disability programme. Work was found, by Ina going on our local television news programme to "sell himself", and telling the public what his skills were. We received a phone call straight after he appeared on television, and Ina has been working for this company ever since. He is still not keen to do much advocacy work for the disability sector, or to be involved at all, but has helped out on occasions. This awareness of himself I think is something to be commended, as Ina has made his decision on how he wants to be perceived by the community, which is the way he perceives himself. Person first!

## CONCLUDING REMARKS

In this paper I have written about my personal experiences here in the Cook Islands. I have seen some wonderful progress throughout the years, even though it has been inconsistent. It is hoped that disability programmes that have recently been developed continue to move forward and that they follow the vision that our Ministry of Education has taken the lead in, which is "inclusion" by mainstreaming our children with special needs within the schools. The ongoing financial support that has been received from NZAID for these projects has made it possible for this vision to develop and strengthen over the years.

The same philosophy has been designed for our adult programmes, with the goal to develop individuals' skills and get them out into the community. The Cook Islands is a small country and we have the potential to become a leader in "inclusiveness" as we are small enough and caring enough. We just need to work together and keep the vision of an "inclusive society".

Inclusion in the Cook Islands is beginning, buildings are slowly becoming more accessible, and people with disabilities are becoming more visible, with children now included in regular schools. Although the process has been slow, it is happening, and we can only now begin to appreciate the hardship and exclusion that this minority group has lived through, and for some, continue to live through. Acceptance is a basic human need which we all strive for yet, for some reason, it can be hard to give. Let us start early and develop these qualities with the young, and hopefully they will become our role models for the inclusive, accepting people of the future.

Kia orana e kia manuia.

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Donna is an occupational therapist and team leader for the Cook Island Disability Action Team. Her current role is the implementation and coordination of the Cook Island disability policy and action plan which is a project initiated and funded by NZAID and AUSAID in partnership with Cook Island Internal Affairs and Cook Island National Disability Council. Her past employment has included being the local special needs advisor within the Cook Islands Ministry of Education, and a special needs teacher/classroom teacher at Te Uki Ou School, Cook Islands. Donna also worked in the late 1980s as the assistant supervisor at the Cook Island Disabled Person Centre, which has given her a good understanding of progress to date for people with disabilities in the Cook Islands.

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