



KNOWLEDGE
ACCESSIBILITY



PROFESSIONAL DEVELOPMENT
OPPORTUNITY

#Healthcare4All!

UNDERSTANDING THE NEEDS OF PERSONS WITH
DISABILITIES WHEN ACCESSING HEALTHCARE IN BELIZE

MAY 2018



INFORMATION AND SUPPORT
EMPOWERMENT



INCLUSION
PARTICIPATION



REALIZE



Foreword

This community consultation, report and recommendations has been undertaken by Realize, a not-for-profit organisation based in Belize and the United Kingdom which works to support the inclusion of individuals with disabilities in all aspects of society within Belize, particularly in accessing healthcare, education, employment and leisure.

We are grateful for the support of all the individuals with disabilities, their families and carers who trusted in Realize to share their experiences, and kindly participated in the consultation. We also recognise the input of key individuals and organisations including the Ministry of Health, Belize Council for the Visually Impaired, Belize Assembly for Persons with Diverse Abilities, The Inspiration Center and Hillside Rehabilitation Center. Without their invaluable participation, this research might not have been possible.

In particular, Realize is grateful for the work of Kate Winser who kindly volunteered her time to make this project possible.

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Summary

This report is the first wide-ranging analysis of the experiences of individuals with disabilities as they access healthcare in Belize. The insights were gathered through interviews, surveys and secondary research which explored the perspectives on individuals with disabilities, their parents and carers and healthcare professionals.

The population of individuals with disabilities in Belize is significant and growing, however they are often at the fringes of opportunity with considerable barriers in place in accessing healthcare, education, employment and leisure.

This report found that:

1. Individuals with disabilities and their parents and carers do not feel welcome when accessing healthcare services
2. Appropriate treatment pathways are frequently inaccessible to individuals with disabilities and their parents and carers
3. The financial barriers to accessing healthcare are prohibitive in many cases for individuals with disabilities and their parents and carers

These barriers result from the combination of a range of factors – including a limited inclusive care culture, lack of general and specialist knowledge, and communication and engagement challenges.

As a result of the insights contained within this report the following recommendations are made:

1. For training in disability awareness and inclusion, covering lifespan of care – from antenatal to palliative care – to be part of pre-qualification for healthcare professions
2. For those already qualified to receive continuing professional development which focuses on disability awareness and inclusion, covering lifespan of care – from antenatal to palliative care
3. For all staff within healthcare services to receive communications and awareness training to support them to engage more effectively with patients with disabilities and their families
4. For a disability champion to be designated in every healthcare centre to act as a patient advocate and support
5. For an accessibility audit to take place which assesses physical and communications barriers in all healthcare centres
6. For a quality assurance process and awarding of a quality mark in recognition of best practice in relation to providing services to patients with disabilities
7. For information and resources on disability to be disseminated to healthcare professionals to support their knowledge of services available
8. For accessible information on good health and well-being to be made available for individuals with disabilities and their families and carers
9. For a general disability awareness campaign to take place to raise broad awareness of the needs and aspirations of individuals with disabilities

10. For individuals with disabilities and their families and carers to receive financial support to meet the costs of healthcare
11. For palliative care to be formalised within state healthcare provision with accompanying focused training to take place in support of palliative care services
12. For bereavement support and counselling to be made available within state healthcare provision

The report concludes with a series of practical steps which Realize is undertaking in order to support the realisation of these recommendations.

In addition, it is concluded that a collaborative platform which brings together all groups, organisations and individuals who wish to see inclusive care needs to be formed in order to build sustainable change – the responsibility does not lie with any single organisation but rather in the coordinated action of the many.

About #Healthcare4All

WHY DOES ACCESS TO HEALTHCARE MATTER?

WHAT DO WE WANT TO ACHIEVE WITH THIS
REPORT?

The right to access healthcare

Access to healthcare is a fundamental human right which every individual regardless of gender, race, age or personal circumstance is entitled to receive.¹ Unfortunately however, this right to access is one which is not enjoyed by all, with individuals with disabilities experiencing a higher lack of care relative to those who do not experience disability.² Globally there are estimated to be over 1 billion individuals who have some form of disability, equating to approximately 15% of the worldwide population³, a proportion which is steadily increasing due to ageing populations and advances in medical care at all stages of life.

The impact which having limited access to healthcare can have on the lives of individuals with disabilities is profound. If an individual experiences limited access to healthcare it may:

- Exacerbate their primary health needs related to their disability
- Result in secondary conditions presenting which are linked to disability
- Limit the diagnosis of co-morbid conditions which are unrelated to their disability
- Increase vulnerability to age-related conditions

Global trends suggest that individuals with disabilities seek medical care at a higher rate than individuals without disability but experience a greater likelihood of their needs being unmet.⁴ As a result, it is likely that individuals with disabilities will experience greater barriers to accessing education, employment and leisure opportunities due to their health needs not being met, as well as experiencing increased higher health risk behaviours due to not accessing health promotion and prevention services.⁵ A vicious cycle can ensue which leads to a lack of positive participation within an individual's community, unemployment and high rates of poverty for both the individual and their primary caregivers and a lack of participation within the education system. All of which results in higher dependence needs which adversely impact on family and social support networks.

Typical barriers to accessing healthcare globally include:⁶

- Lack of opportunity
- Healthcare standards
- Financial barriers
- Absence of inclusive practices
- Physical access to health care settings, including transportation
- Exclusion from direct involvement in care and decision-making

Within Belize there is little clarity on the experiences of individuals as they access healthcare. With little data to draw on it is challenging to understand where services excel or can be developed, and which barriers are most critical to focus on. The #Healthcare4All project is an attempt to draw together the first-hand experiences of individuals with disabilities, their families and carers and professionals from within the health sector.

The goal of #Healthcare4All

The goal of this report is to provide an insight into the healthcare provision for individuals with disabilities and the way in which they experience healthcare.

It is hoped that this report can provide a springboard from which services and support can be developed both by Realize and other organisations. Through gaining a perspective on the provision that exists the intent is to identify where additional services, approaches and perspectives can fill gaps and where current services can be leveraged to develop a more holistic and coordinated response to meet the critical needs of individuals with disabilities.

Guided by the principles of inclusion and belief that every individual, regardless of ability should expect and deserves equal access to healthcare and that healthcare should be provided with timeliness, appropriately, with compassion and without prejudice this project and resulting actions are intended to:

- Raise awareness of the needs of individuals with disabilities in Belize
- To provide a vehicle for individuals with disabilities in Belize to self-advocate, enabling them to have a voice, be understood and feel valued
- To identify what is working well in healthcare for individuals with disabilities in Belize
- To identify the challenges for individuals with disabilities in accessing healthcare in Belize
- To identify the key providers in Belize who specialise in offering specific healthcare for individuals with disabilities
- To make recommendations based on the findings of how healthcare in Belize can be improved to be more accommodating and inclusive of individuals with disabilities.

All data and insights collected have been contextualised within the Belizean social environment and landscape and benchmarked against good practice in the disability sector elsewhere. This report is not designed to be a definitive document in presenting the healthcare provision within Belize, but to add to the existing if somewhat sparse analysis of disability services and present a narrative which represents the trends, challenges and needs that exist in Belize.

When my son was born, I knew something was wrong. The doctor told me it was because I argued with my husband during pregnancy. I blamed myself and knew I just needed to keep my baby safe. 7 years later I found out he has cerebral palsy.

A patient's story

Individuals with disabilities in Belize

WHO IS THE COMMUNITY OF PERSONS WITH
DISABILITIES IN BELIZE?

WHAT IS THE STATUS OF INDIVIDUALS WITH
DISABILITIES IN BELIZE?

Recognising persons with disabilities in Belize

There is no uniform definition or classification of disability in Belize which creates challenges in studying the scope of individuals with disabilities. Figures ranging from 2-26%, are reported depending on which study is examined. This poses a major challenge in planning, implementation, monitoring, and evaluation of programs or even policies that need to be put in place. There are a range of disability support models used in Belize, including the charity model however more so in recent years the social model has been adopted as put forward by the World Health Organisation.

With figures varying, the most common figures tend to suggest 5.9% Belizean population experience disabilities, with the highest percentage living in Cayo (29%)⁷. However, due to underreporting and low diagnosis rates this may be an underestimate. With no change in the disability risks as measured in the 2000 Census, it is estimated that the percentage of persons with disabilities in Belize will rise to 9.5% by 2025 and 14.6% by 2050.⁸

36.4% of children age 2 to 9 in Belize are at risk of having one or more disabilities such as physical, auditory and visual impairment, learning disability or intellectually challenged. Children in rural communities are at a higher risk than children in urban areas; 41.4% to 28.3%.⁹

The status of individuals with disabilities in Belize

Belize has signed and ratified the Convention on the Rights of Persons with Disabilities however no legislation has been enacted which specifically supports the rights of person with disabilities. In the absence of a Disability Act the rights of all individuals to experience non-discrimination are enshrined within the Belizean Constitution, and the Families and Children Act which provides for the support and protection of children makes specific reference to children with disabilities but only insofar as it directs the State to ensure that children with disabilities are afforded equal opportunities to education and requires parents to seek assessment and treatment for children with disabilities.¹⁰

International Disability Rights Monitor *Report of the Americas 2004* concluded that Belize was one of the least inclusive nations in the Americas with regard to disability and lacked the basic elements necessary for the social inclusion of people with disabilities.¹¹ Belize stands out as the only country in the Americas which provides no legal protections specifically for people with disabilities.

Within Belize, the perception of disability is changing, however there is still underlying stigmatisation present which impacts on individuals' ability to access services and the standard of service delivery which they are offered. There is an increased desire to develop inclusive services, as evidenced by the Regional Conference on Children with Disabilities held in Belize City in October 2016 and the recommendations and Call to Action¹² which were issued as a result, however cultural and institutional inertia leads to slow progress in effecting tangible change. In Belize, there is still an urgent need to raise awareness around disability, include individuals with disabilities more fully in society and create opportunities for them to be wholly accepted and empowered within their local communities.

#Healthcare4All uncovered

HOW DID WE DO OUR RESEARCH?

WHAT DID WE FIND OUT?

When I go to the clinic for anything I get asked ignorant and insensitive questions – “Are you blind?” or “What happened to your eyes?”. Often, I get let down at the last minute with cancelled appointments - it is not easy for the blind to move around, therefore when health professionals cancel my appointment last minute after I’ve been waiting for hours or they turn up late, there is not that understanding of the physical and financial implications it took for me to get to my appointment.

A patient’s story

Our research – how we did it

40 individuals with disabilities, both children and adults, parents and carers and healthcare professionals took part in the consultation. Realize undertook the consultations through a range of methods in order to gain the broadest perspectives. Face-to-face interviews with individuals with disabilities (both children and adults), their families and carers and health professionals took place in Cayo District and Belize City. An online survey tool, accessible through the Realize website and disseminated by partner organisations and individuals, was used to gain input from individuals with disabilities, their families and carers and health professionals from across the country. In addition, Realize conducted secondary research using all relevant and available research, reports, and documents including the SITAN of Children with Disabilities (2013), Sitan of Children and Women (2011), Regional Partnership for Children with Disabilities Conference Report (2016) and various international studies for benchmarking purposes.

In order to maintain focus, the thrust of the research revolved around three key areas:

- Neonatal and earlier years healthcare¹³
- General healthcare provision (non-specific to individual disabilities)
- Palliative care

These were selected as areas of focus due to the likelihood of individuals with disabilities being overrepresented in needing to access care at these points. In addition, we focused on public healthcare services – however many of the findings and insights obtained are of relevance to both public and private healthcare provision.

Given the need to ensure that the experiences of individuals with disabilities are at the forefront of the findings of this report, the face-to-face interviews and online survey centred around three key questions:

- What do you think the challenges are for individuals with a disability and their families in accessing health care in Belize?
- What do you feel works well and that you would like to see continue in the health care system?
- What are the changes you would like to see happen and do you have any thoughts on how you would like to see this happen?

All responses have been anonymised and correlations have been drawn which have directly led to the findings below. While recognising that every individual is different and has varying healthcare needs, the intent of the report is to draw out trends which are common to all and which represent significant barriers and opportunities to accessing healthcare.

Key findings

Over and above the key findings below, a universal perspective came through all forms of research. It was the view of all respondents that:

- Individuals with disabilities need to be increasingly visible within society
- The voices of individuals with disabilities need to be heard
- The needs of individuals with disabilities need to be more greatly understood and respected
- Persons with disabilities need to be appreciated as unique individuals and not identified or labelled by their disability

All participants expressed the need for significant change in Belize, as there remains much stigmatisation, lack of awareness and a paucity of education and training surrounding the needs of individuals with disabilities.

I. Individuals with disabilities and their parents and carers do not feel welcome when accessing healthcare services

The overwhelming majority of individuals with disabilities and their families reported reluctance to engage with healthcare services due to prior negative experiences. Many preferred to seek support from family members or friends, access medical care abroad or manage medication and support independently. However, individuals and families did also report instances of good practice which are illustrative of the ways in which positive adaptation in response to the needs of person with disabilities can greatly improve the chances of accessing healthcare.

The reasons for withdrawal are based on cumulative experiences attempting to access healthcare – parents with older children with disabilities and adults with disabilities were more substantially withdrawn from accessing healthcare than those with younger children who had not yet built up the cumulative experience. However, all groups reported the same experiences which suggests that those who have not yet withdrawn from healthcare are likely to follow the same path.

The negative experiences which led to this response are:

- **Inappropriate use of language**
The basic point of communication between patients, parents and carers and healthcare professionals is in the language that is used as part of conversation and discussion. Respondents shared that their experience was that derogatory, negative, non-inclusive and that at times aggressive language was used towards them while accessing care.

This ranged from directive language as assertion of authority to insensitive comments and questioning which was of little or no relevance to that particular healthcare scenario. Implications and statements that patients with disabilities would not understand a medical professional's comments because of their disability were also experienced extensively.

It is clear that the language individuals with disabilities experience, as more vulnerable individuals, becomes a significant barrier to accessing healthcare.

I am deaf and the doctor said I should pour hydrochloric acid in my ear and it would work again.

“That is one freakish arm you’ve got there!”

“So, are you blind? How did you get like that?”

“What happened to your child?!!”

I was in pain, but I was told
“You’re fine, shut up!”

Some things patients have been told
when trying to access healthcare

“There is no compassion!”

“Involve people”

“Health professionals are not exposed enough to people with disabilities”

“Old culture ways dominate over current health training”

“Only option was to leave the country!”

“Involve the kids more”

“Health professionals do not understand learning difficulties. They do not make them first priority.”

What patients feel

- **Negative culture of care towards disability**

A universal experience was the barriers caused by medical professionals having limited experience and exposure to disability, resulting in an approach which perceives individuals with disability in an overwhelmingly negative manner.

Individuals and families reported that the primary approach was one of negativity which only acknowledges the challenges of disability but does not reflect the individual as a unique human being, with skills, aspirations and capabilities. In many cases it was felt that healthcare professionals view the live of persons with disability as one of loss and tragedy, rather than one which can be equally fulfilled with appropriate support and adjustments.

This leads to a deficit in compassion during the healthcare process, where the emotions and sensibilities of patients and their families are not considered.

This experience spans a lifetime of encounters, from the feeling that the birth of a child is treated as an inconvenience rather than a joy, through to lack of engagement with primary and secondary health conditions which relate to the disability experience and difficulties in gaining diagnoses on unconnected conditions which are ignored and regarded purely as symptoms of the disability.

In relation to initial diagnosis of disability, parent and carer experience is that little thought is given to the emotional impact of diagnosis, both for the individual and the parent – while technical medical information may be conveyed there is little or no time spent on considering what the implications of a condition might be and signposting to resources or knowledge which could help families come to terms with the conditions their children are experiencing, or for those who acquire a disability as adults there is little engagement with the emotional and psychological trauma that may be experienced due to a life-changing disability being experienced. This lack of emotional care follows through all the way to end-of-life care with no bereavement support formally available.

- **Poor communication of information**

The tendency for healthcare information to be communicated in overly technical ways and language has become a disincentive for individuals with disabilities and their families to access healthcare. Technical information delivered in a clinical manner does not inform patients appropriately in response to their needs. The information is likely have a high impact, but it is not accompanied by a sense which shows that this has been considered by the professional sharing it – consideration and sensitivity are frequently absent.

In addition to the challenge of language usage outlined above, additional factors come to the fore in relation to sharing information which is of importance to the healthcare of individuals with disabilities:

- Forms of communication: if additional information is shared, it is often in the form of a pamphlet or other form of literature which may be inaccessible to the individual. The time taken to explain the content of the literature is often not taken

- Follow-on information: in particular following diagnosis, further information or discussion of what life may now involve or how families may support a child with newly diagnosed additional needs is not forthcoming. This is also acknowledged in responses from medical professionals who say that they frequently do not know where to find further information or support for patients so are unable to provide what is required.
 - Willingness to engage on other forms of communication: for patients who have communication challenges there is frequent reluctance on the part of healthcare professionals to engage directly with them and use other forms of communication other than talking. This creates a fundamental barrier in accessing healthcare when patient and doctor are unable to communicate.
- **Exclusion from process**

The expectation that patients with disabilities are not to be consulted or have treatment explained to them is an experience that most respondents shared. At the heart of experience is the feeling that individuals have not been given the right to be involved in their own healthcare and given the respect which is afforded other patients.

The severity of exclusion ranges from procedures being undertaken without explanation, such as injections given, or blood taken without the procedure being explained, through to healthcare professionals not addressing the patient directly but instead talking to accompanying parents and carers. More seriously there are many experiences of patients with disabilities not being listened to when articulating symptoms or asking questions.

The absence of a patient-centric approach disempowers all patients, but when working with vulnerable individuals with additional needs it is critically important for them to be involved in the process of healthcare to the degree to which they desire it, and to the extent which means they are comfortable and confident enough to receive care and understand its implications.

- **Lack of adjustments to approach**

In dealing with patients of all needs, the ability for medical professionals to approach each as individuals and adjust their manner of engagement is vital for good healthcare outcomes. When it comes to patients with disabilities there is little to no adjustment in approach when undertaking consultation or treatment.

In addition to the language, approaches and process outlined above, respondents shared reluctance to change systematized approaches which would make healthcare more accessible. For example the refusal to allow an adult with visual impairment to have an individual to provide additional support join them at a hospital consultation is representative of a reluctance to adjust approaches in response to the needs of individuals.

- **Practical barriers**

A range of practical barriers are in place which cause severe impediments to individuals with disabilities accessing healthcare. While some of them may seem trivial they can have a disproportionate impact on patients with disabilities due to the additional needs they experience.

At a logistical level, simple physical access to healthcare can be an obstacle: lack of accessibility infrastructure such as ramps, hearing loops, braille signage, accessible toilets and easily navigable spaces are a fundamental barrier to access. For those who live at some distance from centres of healthcare transportation and the ability to travel the distance required becomes a serious challenge.

At a systemic level issues such as waiting times and cancellation of appointments become highly critical factors. Individuals may find it challenging to wait for hours at a time while waiting for their appointment to take place – this may be due to both physical and behavioural needs. The impact of an appointment cancelled after a patient has arrived at the healthcare centre can have severe consequences, not least a lack of understanding of the effort which may have had to be made in order to arrive for the appointment and the challenge it has presented, but also the financial implications of having to make the journey again or of missing an additional day of work for an appointment to be rescheduled.

In common with the factor of a lack of adjustments being made in terms of care approach, a similar understanding of the adjustments which are required in terms of systems and process would moderate many of these barriers.

2. Appropriate treatment pathways are frequently inaccessible to individuals with disabilities and their parents and carers

While this report is not intended to make an assessment of the technical competence of medical treatment which takes place, it is clear that the treatment received is a major factor in the withdrawal of individuals with disabilities and their families and carers from healthcare. In writing this report we acknowledge the challenge of resourcing healthcare in Belize, however we feel it is important to highlight where individuals with disabilities are disproportionately impacted by this lack of resource.

- **Overly medicalised responses**

Respondents reported that healthcare professionals resort to highly medicalised responses at the expense of exploring more therapeutic treatments. Given the general lack of resource available it may seem counterintuitive, however it may be indicative of reluctance and a lack of confidence to attempt forms of treatment which an individual has not practiced before.

There are accounts of these medical responses leading to highly inappropriate medicine being administered which has no or detrimental bearing on the patient concerned. These could be avoided through the exploration of all appropriate treatment pathways.

In natal healthcare, there were multiple accounts of C-Sections being promoted as a matter of course regardless of need, which then in turn leads to a higher risk for the mother and baby and higher likelihood of separation between mother and child during the first days after birth. This is in line with the C-Section rate within Belize of 34.2%¹⁴, set against a global rate of 18.6%.¹⁵

- **Lack of treatment options available**

A fundamental absence of treatment options was keenly felt by individuals and families. The frequent response is to travel, or wish to travel, internationally for treatment given the lack of possibilities within Belize – this was reflected across surgical, general healthcare and therapeutic needs.

The limited availability or lack of certain forms of treatment, including physiotherapy, speech therapy, specific surgical procedures, mental health support, rehabilitative support, as well as limited availability of diagnostic specialisms left many families feeling that there was little purpose in accessing healthcare as there would not prove fruitful in offering appropriate support.

Within the area of palliative care, it was clear that the sense of limited options was further enhanced due to the extremely limited availability of formal treatment available. The grouping of palliative care and oncology, and the blurred line between palliative and ongoing care for individuals with high needs, leads to appropriate and necessary support being unavailable. With palliative care dependent on voluntary and informal networks the result is that pain management and other care is inconsistently provided and there is no standardised way in which patients can access the care they need.

- **Under-trained staff**

While respondents were not in a position to be able to provide a detailed perspective on technical ability of healthcare staff they nonetheless were able to describe clear aspects where the lack of knowledge and training that was necessary to provide appropriate support was apparent.

The clearest area is in the lack of appropriate specialists available to meet the broad healthcare needs that are required. Specialists such as speech therapists, physiotherapists and specialists in diagnosis were particularly noted. A dependency on short term visits by specialists from overseas underlined the challenges in sustaining consistent and ongoing treatment.

With regards to human resource available, in addition to the need for international healthcare professionals to provide short term solutions, there is a consistent dependence on staff to volunteer beyond the scope of their roles to provide required services in a less formal context. This was particularly noted within the area of palliative care.

My son was diagnosed with autism when he was 3 years old. I didn't know where I could get help and wasn't able to find anywhere that would support me. The doctors prescribed expensive medication for him which I discovered was for dementia and no use for him. My only choice was to leave Belize to get good quality treatment and support for my son in the form of speech and language therapy and special needs classes. Since coming back to Belize I can see that the support still isn't here.

A patient's story

Beyond core staffing needs, additional signs of lack of training were clearly felt in the communication skills and ability to engage with patients with disabilities outlined above, but there were also doubts raised around the capacity of healthcare staff to engage with practice that reflected latest approaches to disability. This potential resistance to absorbing new standards also was perceived in some approaches to current general healthcare standards, such as consistent sterilisation of equipment and cleanliness and the perpetuation of medical “myths”, such as a “bone being in the way” during childbirth leading to pressure for C-Sections to take place.

- **Lack of resources**

The apparent lack of human resource in providing support to patients with disabilities is also reflected in a lack of material resources. Outdated equipment and a heavy reliance on donations of items undermines the potential for sustained and appropriate care, and does not allow for patients to receive care which fully meets their needs.

The inability of families to be signposted towards further information resources is indicative of two factors – the absence of significant information resource available within Belize and the lack of awareness amongst healthcare professionals as to where to direct patients with disabilities and their families.

3. The financial barriers to accessing healthcare are prohibitive in many cases for individuals with disabilities and their parents and carers

For many individuals with disabilities and their families the barrier of financial need is an absolute impediment to accessing care. Whether this is in terms of accessing services or meeting ongoing medicine, therapeutic or treatment needs families frequently are unable to afford to provide the care that is required.

Families of individuals with disabilities are likely to experience a higher financial burden not including healthcare costs – a primary caregiver is unlikely to be able to be employed and bring income to the family, and there are a range of other financial restrictions such as suitable housing, transport, diet and general care needs to be met. Once the factor of enhanced healthcare needs is accounted for it is likely that many families are prohibited from accessing the full range of services that may be needed.

While families and individuals with disabilities will push themselves as far as possible to provide the appropriate level of healthcare, at times it simply is just not possible.

While a range of volunteer and goodwill services are available, these cannot cater to all needs in a sustainable manner and the word-of-mouth nature of referral means that many individuals are left out of the loop. With no differential in healthcare costs based on disability or employment status it is felt by families of individuals with disabilities that they are subject to an excessive financial burden.

Healthcare providers are also sympathetic to this need but in turn do not have any mechanism by which they can fund where individuals and families are unable to pay.

Providing #Healthcare4All

WHAT IS THE SOLUTION?

WHAT DO WE RECOMMEND?

Nobody spoke to my daughter at the hospital. They were really bossy to her and shouted at her when they wanted her to put out her arm for an injection. They didn't even tell her what they were doing. She was terrified.

A patient's story

The solution

In order to ensure that individuals with disabilities are able to access the healthcare provision they need there are a series of fundamental developments which need to take place.

- For an enhanced culture of care towards individuals with disabilities within the Belizean healthcare sector
- For healthcare professionals to have greater awareness of the needs of patients with disabilities and the skill to be able to engage and communicate effectively with them
- For a greater understanding of the care needs and barriers to access which are experienced by individuals with disabilities to be present in policy making and healthcare service development and delivery

During the consultation it was clear that where these foundations are in place, the experience of patients with disabilities in accessing healthcare is considerably enhanced. At the heart of the expectations of patients with disabilities are:

- Engagement with healthcare professionals who are prepared to build relationships
- Simplicity of access to services
- Active consideration of the ways in which provision can be adjusted to specific needs
- Certainty that the medical care and technical knowledge that is being shared is of relevance and value

While the fundamental developments outlined above require long term strategic action, more immediate actions can take place which will improve access to healthcare for individuals with disabilities.

Key recommendations

1. For training in disability awareness and inclusion, covering lifespan of care – from antenatal to palliative care – to be part of pre-qualification for healthcare professions
2. For those already qualified to receive continuing professional development which focuses on disability awareness and inclusion, covering lifespan of care – from antenatal to palliative care
3. For all staff within healthcare services to receive communications and awareness training to support them to engage more effectively with patients with disabilities and their families
4. For a disability champion to be designated in every healthcare centre to act as a patient advocate and support
5. For an accessibility audit to take place which assesses physical and communications barriers in all healthcare centres
6. For a quality assurance process and awarding of a quality mark in recognition of best practice in relation to providing services to patients with disabilities
7. For information and resources on disability to be disseminated to healthcare professionals to support their knowledge of services available
8. For accessible information on good health and well-being to be made available for individuals with disabilities and their families and carers

9. For a general disability awareness campaign to take place to raise broad awareness of the needs and aspirations of individuals with disabilities
10. For individuals with disabilities and their families and carers to receive financial support to meet the costs of healthcare
11. For palliative care to be formalised within state healthcare provision with accompanying focused training to take place in support of palliative care services
12. For bereavement support and counselling to be made available within state healthcare provision

What Realize will do

In undertaking this report we acknowledge the responsibility to play an active role in creating the changes which individuals with disabilities and their families expect. Equally clear is that the solution to accessing healthcare for all lies not in the response of one organisation, but in the collaboration between multiple stakeholders.

In response to the needs expressed in this report, Realize will:

1. Develop disability awareness and inclusion training which can be delivered to healthcare professionals in Belize. This training is anticipated to be delivered in partnership with the Ministry of Health and include developing an understanding of the experiences of individuals with disabilities and effective communication with individuals with disabilities, their families and carers. The training will be developed as a module which can be included within existing training and development programmes, and facilitators will be trained to deliver the material effectively.
2. Develop online training on disability awareness and inclusion for healthcare professionals in Belize which will complement the face-to-face training and act as a sustainable platform for ongoing training and development.
3. Develop communications and disability awareness training which can be delivered to all staff of healthcare centres in Belize. This will be developed as both face-to-face and online modules which can be used to sensitize all staff to the needs of patients with disabilities and their families and carers.
4. Develop an online resource for healthcare professionals which signposts disability resources in Belize and also acts as a knowledge bank for professionals wishing to seek further information about supporting patients with disabilities.
5. Develop a series of tools which healthcare professionals and centres can use to support the inclusion of patients with disabilities.
6. Develop an accessible online resource for individuals with disabilities and their families which provides information on where they can go for support, information on how to best support themselves or family members, and knowledge on specific disabilities.
7. Deliver a programme of training for healthcare professionals involved in palliative care to support their ability in providing appropriate and sensitive care for patients.
8. Develop an online resource which provides tools to support the delivery of palliative care by healthcare professionals in Belize.

Working together for all

HOW CAN WE ALL WORK FOR INCLUSION?

Building inclusion through unity

The challenge of building fully inclusive healthcare provision in Belize is one which requires collaboration across all stakeholders – government bodies, public institutions, NGOs, professionals, the community at large, and most importantly individuals with disabilities and their parents and carers.

There are several recommendations above which would benefit most from the input of a range of organisations in the following areas:

- Professional development and training

The opportunity to integrate inclusive approaches into all areas of professional qualification and development related to healthcare should be explored. Both pre-qualification and continuing professional development provides chances for understanding and exploration of healthcare practices related to inclusion, and these should be fully explored by the institutions which lead healthcare training in Belize.

- Community awareness raising

A coordinated approach to building understanding in the broad community around the needs, aspirations and ambitions of individuals with disabilities is the only way in which a consistent and impactful message can be shared. All stakeholders should engage on a communication strategy which brings together the strengths of each organisation to build a united campaign of awareness raising around disability.

- Development of healthcare policy to provide enhanced spectrum of care

While policy decisions lie with government institutions, these should be developed in partnership with civil society. In the absence of progress on policy, the organisations outside of government should advocate consistently for improved structures, frameworks and approaches – whether these are looking at funding for particular areas of care and training, or looking at social financial support to support access to healthcare.

- Recognition of best practice

Where inclusion is being successfully considered, it is imperative that the community of stakeholders recognises and rewards this. A coordinated group of partners which acts as a platform to give benchmark and credit, whether through awards, quality marks or other forms of recognition, should take a role in congratulating where it is due, and in the process highlight successes and the opportunity for more progress to be made.

A coordinated voice for all organisations, groups and individuals who seek to build change in the lives of individuals with disabilities is required to make the significant changes which are necessary take place. In closing this report, we call on all parties who seek inclusion for person with disabilities to join together in a common forum for action which can create sustainable and permanent changes.

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