Deputy Secretary-General Jan Eliasson
Executive Office of the Secretary-General
Rule of Law Unit, United Nations Headquarters
First Avenue at 46th Street
New York, NY 10017 Email: rol@unrol.org

Special Rapporteur Shuaib Chalklen
Disability, United Nations Enable
405 East 42nd Street
New York, New York 10017
Email: enable@un.org

Special Rapporteur Gabriela Knaul
Independence of Judges and Lawyers
Office of the United Nations High
Commissioner for Human Rights
United Nations Office at Geneva
8-14 Avenue de la Paix
1211 Geneva 10 Switzerland
Email: SRindependenceJL@ohchr.org

May 18, 2014 - by email only

Re: Records Request
For records of contacts made on my behalf,
or that pertain to Neil J. Gillespie

Dear Deputy Secretary-General Eliasson, Mrs. Knaul,
Mr. Chalklen, and United Nations Associates,

On April 23, 2014 I made a records request of the United Nations. A copy of the records request is attached. As of today I do not show a response. Please advise when I can expect a response.

President Barack Obama wrote me March 12, 2014 in response to my letter suggesting specific action by the United Nations under the Rome Statute in lieu of unilateral aggression by the U.S. against Syria. Our correspondence is attached. President Obama provided me a comprehensive response, including a link to U.S. foreign policy on Syria on the White House website.

http://www.whitehouse.gov/issues/foreign-policy/syria

Tellingly President Obama did not mention or respond to my suggestions for specific action by the United Nations under the Rome Statute. Honestly I am surprised President Obama would respond to an ordinary person like me. But the United Nations did not responded to me, and President Obama did not mention the U.N. in his letter, so perhaps I misinterpreted the role of United Nations. If so, I regret any inconvenience to the United Nations. I also regret suggesting to President Obama specific action by the U.N. under the Rome Statute if that was wrong.

Regarding disability, Ms. Zinnah Begum of Bangladesh was born with a craniofacial disorder. Fortunately 58 year-old Zinnah finally got life-changing craniofacial surgery on May 24, 2010 through Touching Souls International for “freedom of smile”,

http://touchingsoulsintl.org/blog/2010/05/24/giving-freedom-of-smile/

A ten (10) page composite for Zinnah Begum accompanies this letter, and includes photos and URL links, a white paper on “The problems of establishing modern cleft lip and palate services in Bangladesh” (The Journal of Surgery, Volume 2, Issue 1, 2004), and a PDF of the World Health Organization (WHO), Global Health Workforce Alliance for Bangladesh.

Ms. Zinnah Begum, Bangladesh. Unfortunately, not all persons are born or created equal.

Social stigma and sadness

Transformation and hope

<u>Article 1</u> of **The Universal Declaration of Human Rights** states,

> "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."
>
> http://www.un.org/en/documents/udhr/

The United States **Declaration of Independence** proclaims "all men are created equal",

> "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness. That to secure these rights, Governments are instituted among Men, deriving their just powers from the consent of the governed."
>
> http://en.wikipedia.org/wiki/All_men_are_created_equal

However it is self-evident that Zinnah Begum was not *born or created equal* because she needed craniofacial surgery since the time of her birth to be "free and equal" in any meaningful way.

It took 58 years for Zinnah to get her face fixed, another fact that also calls into question whether "all men are created equal" or "All human beings are born free and equal in dignity and rights."

Does the United Nations consider Zinnah Begum disabled? Does the U.N. sponsor or facilitate craniofacial surgery? I was not able to find this information on the U.N.'s website. Thank you.

Sincerely,

Neil J. Gillespie

Neil J. Gillespie
8092 SW 115th Loop
Ocala, Florida 34481
Enclosures

Telephone: 352-854-7807
Email: neilgillespie@mfi.net
cc: U.N. email service list

Deputy Secretary-General Jan Eliasson
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April 23, 2014 - by email only

Re: Records Request for UN contacts or records made on my behalf in Petition No. 12-7747 and Petition No. 13-7280, U.S. Supreme Court

Dear Deputy Secretary-General Eliasson, Mrs. Knaul,
Mr. Chalklen, and United Nations Associates,

Thank each of you and the United Nations for your interest in my legal and disability matters brought to the U.S. Supreme Court. Unfortunately my petition for rehearing Petition 13-7280 was denied March 10, 2014. The Consumer Financial Protection Bureau (CFPB) notified me March 10, 2014 that it cannot pursue the Congressional Inquiry of U.S. Senator Marco Rubio, with a referral to HUD, the U.S. Department of Housing and Urban Affairs, PDF attached. HUD and CFPB Freedom of Information Act (FOIA)/Privacy Act responses are attached in PDF.

Forwarded below is my March 13, 2014 email to Mr. Ethan Torrey, Legal Counsel, Supreme Court of the United States, about my March 5th letter to The Honorable John G. Roberts, Jr., Chief Justice of the United States, which is attached, along with letters to the Federal Bureau of Investigation (FBI), and Deputy Secretary-General Jan Eliasson and OPR Counsel Robin Ashton, U.S. Department of Justice.

As of today I do not have a response from the Chief Justice. So I am requesting records that you and the United Nations may have about me and my two petitions to the U.S. Supreme Court, so I can better understand my situation. I trust this email is sufficient for a records request, since I was not able to find a specific records request procedure for the United Nations online.

Thank you in advance for the courtesy of a response.

Sincerely,

Neil J. Gillespie

Neil J. Gillespie
8092 SW 115th Loop
Ocala, Florida 34481
Telephone: 352-854-7807
Email: neilgillespie@mfi.net

cc: U.N. email service list

THE WHITE HOUSE

WASHINGTON

March 12, 2014

Mr. Neil J. Gillespie
Ocala, Florida

Dear Neil:

Thank you for writing. Three years into the Syrian conflict, we face a brutal and protracted civil war, which extremists are exploiting and which poses a threat to stability throughout the region. I am glad you took the time to share your concerns.

The conflict in Syria began as a series of peaceful protests against the repressive regime of Bashar al-Assad. He responded with violence and further repression. Today, over 130,000 people have been killed. Millions have been displaced and are in desperate need.

In response, the United States has stepped up as the largest donor of humanitarian assistance to those affected by the war. Our aid has helped ease the pressures this conflict has put on families and on the region, but international efforts to provide more assistance have been blocked by regime obstruction and insecurity. That is why we continue to demand greater humanitarian access to those in need.

Over the past 2 years, we have also worked with friends and allies to help the moderate Syrian opposition and chart a path to a political resolution. The January 2014 launch of negotiations between the Syrian government and opposition, mediated by the United Nations, was a critical step on that path.

One thing I have said since the beginning is that I will not pursue an open-ended military intervention in Syria. Last year, when the Assad regime violated international law by using chemical weapons in an attack that killed over 1,000 Syrians, I was prepared to respond through narrow and targeted military action. But when a diplomatic option opened up, we took it—because I believe any chance to remove the threat of chemical weapons without the use of force is one we must pursue.

Today, there is potential for progress. American diplomacy, backed by a willingness to use military force, has paved the way for a plan to eliminate Syria's chemical weapons for good. Now, Syria must meet its international obligations to implement that plan, and Russia has a responsibility to ensure that Syria complies. And in the months ahead, we will continue to work with the international community to usher in the future the Syrian people deserve—one free from dictatorship, terror, and fear.

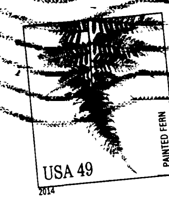
Thank you, again, for writing. You can stay up to date on the conflict in Syria and my Administration's response at www.WhiteHouse.gov/Issues/Foreign-Policy/Syria.

Sincerely,

THE WHITE HOUSE
WASHINGTON, DC 20500

CAPITAL DISTRICT

18 MAR 2014 PM 3 L



Mr. Neil J. Gillespie
8092 Southwest 115th Loop
Ocala, Florida 34481

34481356792

President Barack Obama September 9, 2013
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear President Obama,

There is an alternative to bombing or attacking Syria. You could propose the United Nations:

1. Evacuate the city of Damascus where Bashar al-Assad lives in the Presidential Palace.
2. Immediately relocate the population to protect the Syrian people from further harm.
3. Blockade Damascus to contain Assad and his supporters until they run out of supplies.

Eventually Assad will surrender or be captured and brought to justice under international law.

The Rome Statute applies because Syrian national systems have totally failed. The Prosecutor of the International Criminal Court may open an investigation of Assad on referral by the United Nations Security Counsel, or by a Pre-Trial Chamber. [The United States cannot make a referral because we have not ratified the Rome Statute]. Then Assad may be prosecuted for international crimes, and convicted if the evidence proves his guilt beyond a reasonable doubt. This plan may be a viable alternative to pending unilateral aggression by the United States.

In my view the Slattery Report[1] *concept* should also be considered instead of hostilities, now or in a similar situation. People would support evacuating a civilian population to de-escalate a situation like this one with Assad, so that justice may prevail while protecting the Syrian people.

You were given the Nobel Peace Prize in 2009. Give peace a chance first. Syria can always be attacked later if necessary, and with better moral grounds than you have now. Thank you.

Sincerely,

Neil J. Gillespie
8092 SW 115th Loop
Ocala, Florida 34481

Telephone: (352) 854-7807
Email: neilgillespie@mfi.net

---

[1] The Slattery Report, officially titled The Problem of Alaskan Development, was produced by the United States Department of the Interior under Secretary Harold L. Ickes in 1939–40. It was named after Undersecretary of the Interior Harry A. Slattery. The report, which dealt with Alaskan development through immigration, included a proposal to move European refugees, especially Jews from Nazi Germany and Austria, to four locations in Alaska, including Baranof Island and the Mat-Su Valley. Skagway, Petersburg and Seward were the only towns to endorse the proposal. http://en.wikipedia.org/wiki/Slattery_Report

<u>Giving Freedom of Smile, May 24, 2010</u>
http://touchingsoulsintl.org/blog/2010/05/24/giving-freedom-of-smile/


Tahmina Sultan, RPh, Pres. Zinnah Begum, age 58 Freedom of smile, May 24, 2010

<u>Touching Souls International</u>
P.O. Box 280474, Queens Village, NY 11428
https://www.facebook.com/touchingsoulsintl.org

Life expectancy at birth, Bangladesh m/f (years): 66/69

From *Giving Freedom of Smile*,

"...in a country like Bangladesh a disadvantaged person with cleft-lip may pass their adult life without having the surgery. The patient above, fifty eight year old **Zinnah Begum** had a desire in her life, once she would like to hear from other people that she is not ugly. And Touching Souls International gave her that support, gave her that confidence back, that she is not ugly anymore..."

<u>Group Dhaka Medical College Hospital</u>, Dhaka, Bangladesh http://www.dmc.edu.bd/
http://en.wikipedia.org/wiki/Dhaka_Medical_College_and_Hospital

<u>Dhaka Medical College Hospital Documentary</u> - http://youtu.be/oUeqPPLwXQ4

The problems of establishing modern cleft lip and palate services in Bangladesh
S. Ghani, A. Mannan, S. L. Sen, M. Uzzaman, M. Harrison, Abstract

There are approximately 300,000 cleft lip and palate (CLAP) sufferers in Bangladesh amongst a population of 120 million. The vast majority of these patients cannot afford and do not have access to even basic surgical repairs or cleft related services. CLAP care in Bangladesh is compromised by the lack of a coordinated multidisciplinary care package (MDT) and a shortage of adequately trained surgeons. In January 2002, the Mobile Cleft Lip Camp was set up to address this shortfall. Subsequently camps have been held throughout the country and a total of 467 patients have been operated on over the last 2 years....see full article attached.

Cleft -lip and cleft -pallet is a major problem in developing countries like Bangladesh. The people with cleft -lip and cleft -palletare unable to eat or speak properly for which they have to face an isolated life filled with pain and shame for not being socially acceptable. Touching Souls International offers free cleft-lip and cleft- pallet surgeries for economically disadvantaged people of Bangladesh. Cleft- lip operation gives the person a whole new start of life. Our cleft- lip project is dedicated to optimize the quality of life of individuals affected by facial birth defects.

Management of cleft lip/cleft pallet involves more than surgical repair of the defect. Services of other professionals such as dentist,orthodontist, otolaryngologist, audiologist, and pediatrician are usually required to identify and treat the associated problems. In addition the care is provided by each specialist carefully timed and coordinated in an individualized overall treatment plan. Touching Souls International's volunteer medical teams travel to different parts of Bangladesh where they are hosted by the local hospitals to operate their free cleft-lip camp for the needy.

Touching Souls Internationale's cleft- lip project works in co-operation with Cleft- lip Camp Group of Dhaka Medical College Hospital, Dhaka, Bangladesh. Touching Souls International is an organization which is dedicated for it's philanthropy for the disadvantaged people of third world countries. Since 2001, it has provided thirty six free cleft-lip camp in different districts of Bangladesh. In each cleft-lip camp fifteen to seventy needy cleft-lip patients got free cleft-lip surgeries. For the first time in their life, they get back the freedom of smile. These patients get back a new life to live, not to be ashamed of their God given facial birth defect any more.

In developed countries cleft-lip surgery is done within the first year of a child's life. Whereas in a country like Bangladesh a disadvantaged person with cleft-lift may pass their adult life without having the surgery. The patient above, fifty eight year old Zinnah Begum had a desire in her life, once she would like to hear from other people that she is not ugly. And Touching Souls International gave her that support, gave her that confidence back, that she is not ugly anymore. And Zinnah Begum is so greatful to Touching Souls International for their humanitarian work.

Follow us on Twitter: http://twitter.com/touchingsoulsin

Connect with us on Facebook: http://www.facebook.com/touchingsoulsintl.org

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The problems of establishing modern cleft lip and palate services in Bangladesh

S. Ghani[1], A. Mannan[1], S. L. Sen [2], M. Uzzaman[1], M. Harrison[1]

[1]Guy's, King's and St Thomas' Medical School London, UK,

[2]Dhaka Medical College Hospital, Dhaka, Bangladesh

Correspondence to: Michael Harrison, Department of Orthodontics and Paediatric Dentistry, Guy's, King's and St Thomas' Medical School, London. United Kingdom.

Abstract

There are approximately 300,000 cleft lip and palate (CLAP) sufferers in Bangladesh amongst a population of 120 million. The vast majority of these patients cannot afford and do not have access to even basic surgical repairs or cleft related services. CLAP care in Bangladesh is compromised by the lack of a coordinated multidisciplinary care package (MDT) and a shortage of adequately trained surgeons. In January 2002, the Mobile Cleft Lip Camp was set up to address this shortfall. Subsequently camps have been held throughout the country and a total of 467 patients have been operated on over the last 2 years. The mobile cleft lip camp differs from the majority of other surgical camps in that it is run completely by local Bangladeshi doctors and nurses. Despite their best efforts the Mobile Cleft Lip Camps are not the solution to Bangladesh's CLAP problems. CLAP services are far behind those of the UK. They are in need of quite dramatic modernisation. For the long-term benefit of the 300,000 CLAP sufferers it is important that international organisations, groups and individuals help local medical staff to establish a Bangladeshi Cleft Lip Board and set up an MDT care package suited to the needs of the local CLAP population.

Background

Clefts of the lip, alveolus, hard and soft palate are the most common congenital abnormalities of the orofacial structures [1]. The abnormalities in cleft lip are the direct consequence of disruption of the muscles of the upper lip and nasolabial region. Unilateral cleft lip is the result of nasolabial and bilabial muscle ring disruption on one side whereas bilateral cleft lip is the result of symmetrical defects[1]. Cleft palate is the result of incomplete fusion of the palatine shelves confined to only the soft palate, only the hard palate or both.[1] Patients suffering with CLAP tend to have impaired hearing (chronic otitis media), speech difficulties, misaligned dentition and many require quite advanced orthodontic management in tandem with good primary, and if necessary revision surgery.[1] They frequently occur as isolated deformities - non-syndromic CLAP - but can be associated with other medical conditions.[1] The genetics of non-syndromic CLAP have still not been defined but are thought to be the result of a broken genetic circuit and hence there are a series of defects with particular attention to the orofacial cleft genes.[2]

The incidence of cleft lip and/or palate (CLAP) tends to be much higher in the developing world compared to the developed. The incidence in the UK and US is approximately 1 in 700 as opposed to 1 in 500 in regions of Africa, Asia and South America.[3] [4] Bangladesh has between 275,000 and 300,000 people currently living with CLAP amongst a population totalling almost 120 million[5]. This equates to just over 1 child in every thousand families. The vast majority of these sufferers make up the destitute and poorest segments of society[6].

The problem is exacerbated by the majority of sufferers being unable to afford the appropriate surgical treatment, a significant lack of skilled surgeons able to carry out the necessary procedures (there are currently only[13] plastic surgeons working in Bangladesh), under funded and poorly equipped hospitals, together with social isolation.[6]

Bangladesh has been the beneficiary of numerous volunteer missions where surgeons, notably from the US, Europe, Japan and South Korea, have performed surgical camps for patients suffering from a variety of orthopaedic, ophthalmic as well as plastic surgical complaints.[7] The majority of these camps have also delivered an educational element and have helped some way towards the training of local surgeons. This in tandem with an increased involvement of host surgical trainees has helped to inspire enthusiasm from local health authorities.[8]

The Mobile Cleft Lip Camp

In January 2002, the Mobile Cleft Lip Camp was set up to address the increasing numbers of CLAP sufferers, with the 1st of a total of 32 camps, being held at the Nawabgonj Thana Health Centre (THC - Primary Care Centre) within the outskirts of the capital Dhaka.[9] A total of 9 patients were operated on at this camp, of which, 7 had cleft lip repairs (4 under general anaesthesia and 5 under local anaesthesia).[9] Subsequently camps have been held throughout the country (figure 1) and a total of 467 patients have been operated on over the last 2 years. Amongst them, 433 individuals received cleft lip repairs with the remaining 34 patients being operated on for a variety of other conditions comprising tongue ties, marjolin ulcers, naevi, neurofibromas, polydactyly and papillomas.[9] Unfortunately details of re-repair rates and fistula formation are very scarce as follow up of patients is extremely difficult.

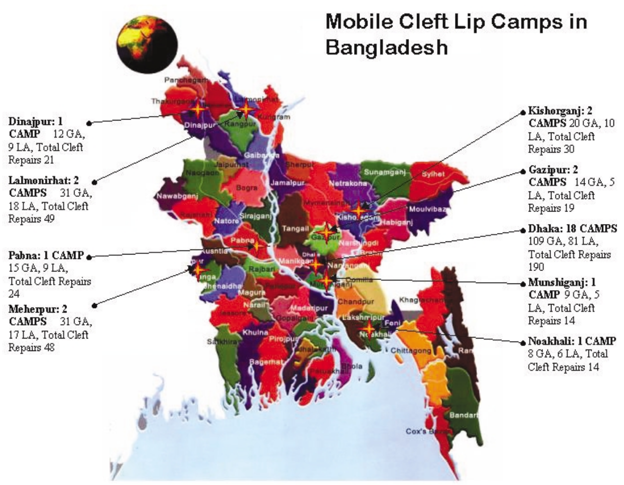

Figure 1: *Map of Bangladesh highlighting the regions in which Cleft Lip Camps have taken place. Unfortunately data on the re-repair rate and complications is not available due to poor auditing.*

Venue	Number of Camps	General Anaesthesia	Local Anaesthesia	Total Cleft Lip Repairs
Dinajpur	1	12	9	21
Dhaka	18	109	81	190
Gazipur	2	14	5	19
Kishorganj	2	20	10	30
Lalmonirhat	2	31	18	49
Meherpur	2	31	17	48
Munshiganj	1	9	5	14
Noakhali	1	8	6	14
Pabna	1	15	9	24
Total	**30**	**249**	**160**	**409**

Figure 2: *A table summarising the results*

The mobile cleft lip camp differs from the majority of other surgical camps in that it is run completely by local Bangladeshi doctors and nurses and comprises a team of 3 plastic surgeons, 2 anaesthetists, 5 nurses and 2 "ward helpers".[10] They are led jointly by Dr Samanta Lal Sen, head of Burns Unit, DMCH, and Professor Khalilur Rahman, head of the Anaesthetic Department, DMCH.[10] The camps have been organised with the financial support of a number of voluntary organisations including Spandan B and Humanity Without Borders, both organisations of expatriate Bangladeshis in the USA, as well as the British Women's Association.[10]

Typical Camp

A typical cleft lip camp involves the team leaving DMCH early in the morning and driving out to the designated village together with all necessary medical supplies. On arrival at the local THC, they set up theatre in a designated room with enough space for at least two tables such that two cleft lip repairs can be carried out simultaneously and in some cases even three. The majority of THCs usually have "dated" anaesthetic machines, theatre lights and operating tables:

Local health care workers have an integral role and will publicise forthcoming cleft lip camps a week before arrival through local newspapers, by loudspeaker transmissions and door-to-door campaigns. Potential patients are asked to attend a pre-operative clinic the day before and a preliminary group of patients are selected and given appropriate pre-operative anaesthetic advice. Selection criteria are vague but the social dynamics of the individual patients tend to dictate selection at this early stage. Priority tends to be given to girls coming from very low-income households. The majority of patients tend to be below the age of 10. However, it is not uncommon for a mother and daughter, to be operated on at the same camp.[9]

Following the team's arrival, they are extremely well received by their hosts. Camps usually last a day with the team returning to Dhaka late in the evening. The anaesthetists perform pre-operative anaesthetic assessments of all the pre-selected patients and finalise the surgical list while the rest of the team prepare the operating theatre. Children are usually given suppositories and anti-emetics but no antibiotics or post-operative assessments are deemed necessary.

Where possible and safe, three patients are operated on at any one moment. Similar anaesthetic-surgical protocols have been used in the past by a number of international groups visiting countries in Africa and the Indian subcontinent.[11] Lack of a recovery area means patients have to be taken back to the ward following their repair where nurses monitor them. They are kept in over night and advised to take lots of fluids for the rest of the day. Cleft palates are not repaired at these camps and instead patients are asked to attend clinics at DMCH. Stitches are removed a week later by local medical staff.

The mobile cleft lip camp performs repairs for free and is a Godsend to the many poor CLAP sufferers. They also serve as a valuable educational and training experience for younger surgeons.

Multidisciplinary CLAP care in the UK

Cleft lip and palate services in Bangladesh can be put into perspective by comparing them to those in the UK. The complexity of CLAP demands the skills of a multidisciplinary team of professionals to optimise surgical outcome.[7,8] Such a care package was accepted and established by the government following recommendations in a report on CLAP by the Clinical Standards Advisory Group (CSAG) in 1998.[12] CSAG's main recommendation was that the expertise and resources for cleft lip and palate services should be concentrated within a small number of designated centres throughout the country. These designated centres or "hubs" should also have "spoke" arrangements (services provided in the community) to ensure optimal accessibility without compromising the quality of care.[12]

Over the last 4 years the quality and level of care for CLAP patients has improved significantly in the UK and the current care package for a newly diagnosed patient is required to fulfil a minimum set of criteria.[12] These consist of a comprehensive service with good communication at all levels and a multitude of specialities working together including plastic surgeons, maxilofacial surgeons, orthodontics and dentists, speech and language therapists, audiologists and otolaryngology specialists as well as clinical psychologists and geneticists.[13]

Government funded CLAP services in Bangladesh stop well short of those provided in the UK.

Case Study 1:
Bhairab Bazar THC - 10th August 2003
Patient AC

Patient AC was an 8-10 year old male. He suffered from unilateral cleft lip and complete cleft palate with associated misalignment of dentition. He was unable to speak coherently as a result of velopharyngeal incompetence producing “hypernasal” speechand he had extensive difficulties with articulation. AC appeared to have further dysmorphic features consistent with Fragile X Syndrome, including prominent ears and relative macrocephaly. His development had been affected and was illiterate. On further questioning he demonstrated poor hearing and gave a vague history of chronic otitis media. He was clearly very malnourished. AC was not operated on due to his late arrival.

Figure 3: *Dysmorphic features consistent with a differential diagnosis of Fragile X Syndrome. Boy 1 had a unilateral cleft lip with a complete cleft palate and extreme misalignment of his dentition.*

Case study 2:
Bhairab Bazar THC - 10th August 2003
Patient NE

NE was amongst the 16 patients to be operated at the Bhairab camp. He presented alone on the evening before. NE was 15 years old and suffered from unilateral cleft lip, complete cleft palate and hypodontia. He was also unable to speak clearly with velopharyngeal insufficiency and poor articulation skills. He was attending school but had fallen some years behind his peers. He reported no family history of CLAP. Surgeons were very keen on the Delaire Technique and sequence.[14] Cleft lip repair was successful. With poor follow-up of the campís patients, NE will not receive any counselling, speech therapy, orthodontic treatment or any necessary revision surgery. Furthermore medium to long-term complications will not be recorded and he will most likely not benefit from any multidisciplinary care. However,NE is satisfied with this current degree of aesthetic improvement despite continuing functional problems.

Figure 4: *NE, 15 years old, had a unilateral cleft lip and complete cleft palate. He had a successful cleft lip repair at Bhairab THC.*

Discussion

There is a significant difference between the technologically advanced MDT CLAP care package available on the NHS compared to the sparse services in Bangladesh (figure 5). In the UK, CLAP is diagnosed following antenatal screening and family adjustment is made easier thanks to counselling and neo-natal nursing.[12] In Bangladesh parents are first made aware of their childrenís abnormality following delivery when they see their child for the first time.

The consequences of no speech and language therapy and poor audiology services in Bangladesh are ramatic. Poor services lead to poor communication and illiteracy amongst those affected by CLAP. In turn, this may lead to poor self-esteem and truancy, which then results in no real chance of upward mobility in a country with high unemployment and poor economic growth.[15] A significant proportion of children attending the cleft lip camps do not achieve their full developmental potential.

Genetic counselling, psychological counselling, and advanced preventative and restorative dentistry services are expensive and limited in availability and scope in Bangladesh.[16] It is not clear why the majority of CLAP sufferers are from poor rural backgrounds and whether or not there is a genetic component to this. Women in Bangladesh get married, on average, at the age of 14 with 63% of women giving birth before the age of [20,17,18] A significant number of “teenage” pregnancies and the potential presence of unidentified teratogens may account for the majority of CLAP sufferers being from the poorer segments of society.[19] However, this is in contrast to the findings in Sri Lanka where social status was found to have no association with the occurrence of clefts.[20]

It is also equally unclear how many CLAP patients are presenting as syndromic or non-syndromic cases. Unlike Pakistan, the incidence of consanguineous marriages is much less and hence does not contribute as much to the aetiology of CLAP in Bangladesh.[21] As was the conclusion in Sri Lanka, the aetiology of CLAP in Bangladesh is most likely to be multifactorial.[22] Local beliefs suggest that children with CLAP are born to mothers who cut fish and vegetables on the night of a full moon when pregnant. As a result many mothers feel responsible for their child’s condition and are alienated by the rest of the family.[6]

Efforts to bring CLAP services in the UK and the developing world closer together are considered by some, to be well intentioned at best [22]. The sole export of surgical expertise to disadvantaged regions of the world can be viewed as being irresponsible and unhelpful in the long term.[23,24] Any surgery performed is only a single step in the CLAP treatment pathway. Patients are still left with severe functional problems such as poor articulation and severe dental problems; aesthetic improvement alone is not enough. Patients require more long-term and consistent help and that can only come from local doctors, dentists and speech therapists. Volunteer groups need to be prepared to address these issues and at least advise local health authorities of how to start to tackle such major deficiencies.[24] They must also not underestimate the abilities of their local counterparts.[25]

Some surgeons believe that a lack of a long-term outlook amounts in many ways to medical colonialism - allowing guest participants to profit directly in a fashion not possible at home.[24, 26] In other words it is an opportunity for less experienced and qualified surgeons from abroad to practice and fine-tune their skills unsupervised, on needy local patients whose threshold for success is much lower.

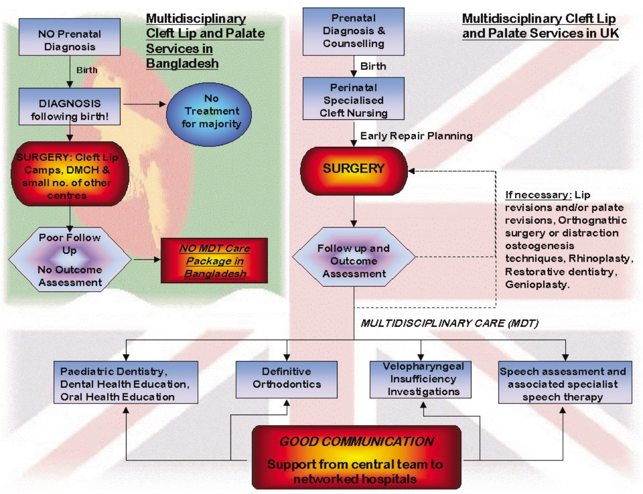

Figure 5: *Flow diagrams summarising the cleft lip and palate care services available in the UK and in Bangladesh.*

A number of models for establishing modern CLAP services in developing nations have been proposed and in some cases put into practice.[27,28,29,30] Zbar et al. proposed a 3-phase system.[31] These phases are continuous and consist of observation, integration and independence.[32] With advancement from one phase to the next the involvement of host medical staff increases as the guest team's direct influence decreases culminating in independence. Without a long term plan set out there is always the potential for misdirection and stagnation at each phase. Good communication and clear aims and objectives are paramount and if adhered to can yield success. An example of this is Nepal where CLAP services, previously non-existent, are currently at Phase II and slowly progressing towards final independence with much of the needs of the local CLAP population being provided by local surgeons and other local members of the newly formed MDT team.[29]

Bangladesh CLAP services are difficult to define using this model. The cleft lip camps are a Bangladeshi alternative to foreign volunteer missions. Instead of foreign surgeons travelling to rural regions and providing much needed surgery, Bangladeshi surgeons, trained by foreigners, are travelling from DMCH to rural areas to perform surgery. However, there has been no effort to centralise CLAP services, which has been shown to be more effective in the UK.[12] This has proved to be difficult due to the absence of a cleft board able to coordinate CLAP services on a national level. Efforts to centralise services are also hindered by a lack of development at local village level and poor infrastructure compromising communication and any potential referral system.[14]

The introduction of the cleft lip camp has provided an extremely valuable training opportunity for younger local surgeons. An integral part of the camps involves active training and guidance of younger members of the team whilst not encouraging medical colonialism. Unfortunately a lack of an MDT approach means treatment is almost entirely surgically led. Hence staff at the local THC are not as involved in the training programs. As a result their roles in the treatment of CLAP patients are less dynamic and more stagnant. Until this is rectified and the importance of MDT care fully acknowledged, there will be little progress towards Phase II and III. However, it is important to note that the aim of the Camps is to treat as many patients as possible and in this respect it is a complete success. They were not set up to address the need for a national CLAP care package.

The general population display a very negative attitude towards medicine and doctors in Bangladesh. Doctors are considered to be more interested in making money rather than treating patients.[33] The Mobile Cleft Lip Camp demonstrates awareness of the CLAP problem by surgeons in Bangladesh. This has been appreciated in the national press. Never the less the Mobile Cleft Lip Camps provide only a very temporary solution and are a success only to those patients they manage to treat. To safeguard their long-term effectiveness it would be prudent for them to adopt the recommendations made recently, by the International Task Force on volunteer cleft missions.[34] Based on data collected and a common consensus, this committee outlined their recommendations based on mission objectives, organisation, personal health and liability, funding, trainees in volunteer cleft missions and public relations.

The main aims of the cleft lip camps should be firstly to provide a local high-quality surgical service. Secondly they should focus on training young surgeons and more importantly local THC staff. The involvement of rural doctors more in the treatment of CLAP and its long term complications will help to develop a drive towards MDT care as opposed to being entirely surgically led. Thirdly surgeons should be encouraged to perform some research. With a quarter of a million babies born with CLAP each year there is a global need for new treatment and research strategies for the improvement of care of these patients.[35] There is an urgent need for more randomised clinical trials (RCT) to evaluate the outcomes of treatment so that clinical guidelines and treatment protocols are based on strong evidence.[33] Epidemiologic data collection and analysis, genetic data collection and analysis, and RCTs of treatment provided at the camps should be actively encouraged.[36] There also needs to be a change from the "body count mentality" and accurate auditing of camp results as well as complications and re-repair rates instigated.

Currently there are a handful of different CLAP teams (the Mobile Cleft Lip Camp being only one) operating in different regions of the country. They all have quite different opinions about how best to deliver an efficient CLAP service and do not interact with each other. Members of the Cleft Lip Camps believe surgical expertise should be taken to the patients for simple procedures such as cleft lip repairs. At this point they are able to pick up patients in need of cleft palate repairs and other more complicated procedures and hence provide them with a referral to DMCH.[10] Advantages of this system are that the patients receive good initial assessments from specialists as opposed to less experienced THC medical staff. Also they do not have the burden of having to travel to Dhaka - a burden that many cannot afford.

Groups from Chittagong (southern port city) believe patients should always travel to centres of surgical excellence, where cleft lips and palates can be operated on simultaneously.[12, 37] This also allows for patients to be seen by dentists and speech therapists at the same time and their treatment is more multidisciplinary in nature. The Mobile Cleft Lip Camps have recently started to invite dentists and other specialists to be involved in their efforts. However, this has not been as successful as a centralised approach.

The establishment of a cleft board to discuss, debate and unite these various groups would help to standardise a form of CLAP management best suited to the needs of Bangladesh.[24] This would also be the first major step towards modernising CLAP services. This should be very possible as there is already in existence the Society of Surgeons of Bangladesh. One of their aims is to create and maintain a spirit of unity, cooperation, solidarity and fellow feeling among the surgeons of Bangladesh, other members of the Medical Profession and other workers in the service. Therefore the establishment of a cleft board could merely be an offshoot of the Society of Surgeons of Bangladesh.[38]

Recently attempts have been made to unite CLAP services in the country with the Islami Bank Hospital and Rajshahi Medical College Hospital (both in Rajshahi, Bangladesh), organising a seminar on Cleft Lip management in Bangladesh in September 2003. Speakers emphasised the need for a coordinated effort from all authorities to extend and unite their services to solve the problems of 300,000 untreated CLAP sufferers in Bangladesh.[39] Bangladeshi surgeons are best placed to judge the needs of the local CLAP population as well as what sorts of services are possible within the tight constraints of the local healthcare service. Advice from foreign surgeons and volunteer groups will help a united Bangladeshi cleft board to develop a deliverable service.

Conclusion

CLAP services in Bangladesh are far behind MDT services in the UK. They are in need of modernisation as well as a healthy injection of funding and a change in attitudes towards MDT care. Thus far a handful of local and international plastic surgeons have tried to create short term, and in many ways successful, solutions with the mobile cleft lip camp being one of them. However, for long-term benefit it is important international organisations, groups and individuals help local doctors to establish a Bangladeshi Cleft Lip Board and produce an MDT care package suited to the needs of the local CLAP population. Local surgeons and doctors are very enthusiastic and this is reflected in the recent set up, with the help of a British plastic surgeon, of the first plastic surgery postgraduate training program in Bangladesh.[40]

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global health workforce alliance

Health workers for all and all for health workers

Bangladesh

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Bangladesh suffers from both a **shortage of and geographic mal-distribution of HRH**. There are an estimated 3.05 physicians per 10,000 population and 1.07 nurses per 10,000 population (estimates based on MoHFW HRD 2011). There is a severe gap between sanctioned and filled health worker positions: 36% vacancy in sanctioned health worker positions and only 32% of facilities have 75% or more of the sanctioned staff working in the facilities (World Bank, 2009). 28% of treatment provided in government health facilities is through alternative medicine (Ayurveda, Unani, and Homeopathy), yet as of June 2011, there was a 50% vacancy rate for alternative medicine providers (MoHFW AMC 2011).

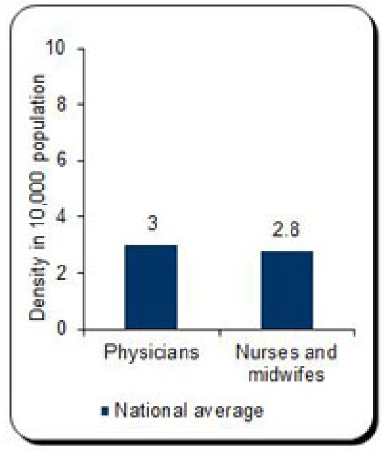
Health workers are **concentrated in urban secondary and tertiary hospitals**, although 70% of the population lives in rural areas (Country Case study (GHWA, 2008). Major challenges include: an overly-centralized health system, weak governance structure and regulatory framework, weak management and institutional capacity in the Ministry of Health and Family Welfare (MoHFW), fragmented public service delivery, inefficient allocation of public resources, lack of regulation of the private sector – which employs 58% of all physicians, shortage of HRH, high turnover and absenteeism of health workers, and poor maintenance of health facilities and medical equipment.

Despite these challenges and the fact that HRH was not considered a priority in the current sector program, there have been **recent successes** including: increase in the number of graduates and health worker training facilities, and an increased number of rural health facilities. The MoHFW prepared its new sector program - the Health, Population and Nutrition Sector Development Program (HPNSDP) and is revising its draft National Health Policy, based on lessons learned from previous programs. Goals include: developing an HRH plan, creating a functional HRH Information System (HRIS), scaling up the production of critical health workers, introducing incentive packages to deploy and retain critical health workers in remote and rural areas, addressing the challenge of skilled birth attendance by training community-based SBAs and/or nurse-midwives and family welfare visitors, and streamlining the recruitment and promotion of nurses (PID, World Bank, 2011).

COUNTRY COORDINATION AND FACILITATION (CCF) IN BANGLADESH:

The first stakeholder dialogue on Human Resource for Health (HRH) in Bangladesh took place on 28th March 2012. The dialogue was mainly to start advocacy on the need of adequate and skilled health workforce for well functioning health system and advocate for the Country Coordination and Facilitation (CCF) process as initiated by the Alliance.

KAMPALA DECLARATION AND AGENDA FOR GLOBAL ACTION PROGRESS



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Progress report on the Kampala Declaration and Agenda for Global Action

COUNTRY MAP

This map is an approximation of actual borders.

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HEALTH WORKFORCE DATA

- The latest data from multiple WHO source
- HRH Data Sheet-2011, Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, Human Resources Development Unit
- Alternative Medicine HRH 2011, Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, Human Resources Development Unit
- Latest statistics available from Government of the People's Republic of Bangladesh Directorate-General of Health Services

HUMAN RESOURCES FOR HEALTH PLAN

A comprehensive HRH strategy is currently being developed by the Human Resource Development Unit of Ministry of Health & Family Welfare, Bangladesh Secretariat (MOHFW).

The past Bangladesh Workforce Strategy (2008) focused on integrating the system of managing and accreditation of HR across the public, private and NGO sectors. Included measures were:

- development of an HR master plan
- improved incentives to work in rural and remote areas
- increased community-focused aspects into training programs, and
- improved quality of health workforce education and planning, including improving the capacity of teaching and training institutions with a shift from a more knowledge-based to skills-based approach.

Other focuses were stewardship/regulation of health HR, recruitment and career development and retention, performance management processes, leadership and coordination of HR functions, public-private partnerships, effective financing and an Integrated Human Resource Management Information System.

- More information

HEALTH SECTOR STRATEGIES / PLANS

The Ministry of Health and Family Welfare is currently in the midst of a dialogue process with the different stakeholders for finalizing the draft document of National Health Policy Health and Family Welfare.There are currently 16 principals and 38 working strategies in the policy including formulation of National Health Development Council to strengthen inter-ministerial health related tasks and provide guidelines in implementing the policy.The specific goals of the policy are ensuring primary and emergency health services for all, expanding equity based quality health services and encouraging people to seek healthcare.

- Directorate General of Health Services (DGHS) sector-wide multi-year development program: Health, Population and Nutrition Sector Development Program 2011-2016 (HPNSDP 2011-2016)

COUNTRY CASE STUDIES & OTHER DOCUMENTS

STATISTICS

Total population: 142,319,000 (unadjusted), estimated 152,111,000 (adjusted)
Gross national income per capita (PPP international $): 1800 (World Bank, data for 2010)
Life expectancy at birth m/f (years): 66/69

Source: 2011 Population & Housing Census: Preliminary Results, Bangladesh Bureau of Statistics

Bangladesh: a Snapshot, Government of the People's Republic of Bangladesh Directorate General of Health Services

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- Bangladesh Trains Health Workers to Reduce Maternal Mortality (2008)
  pdf, 204kb
- WHO Country Cooperation Strategy 2008-2013
- Update Millennium Development Goals (2011)
- Ministry of Health and Family Welfare Performance Report (2009-2010)
- Health Care Network of Bangladesh under the Ministry of Health and Family Welfare (2011)
- MNRH at community level: A profile of Bangladesh (2011)
- MoHFW Health Bulletin 2010
- Review of National and International Experiences with Human Resources Incentive Packages (MoHFW, 2010)

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