

### UNITED NATIONS NATIONS UNIES 21<sup>st</sup> Century

Programme: EPISODE # 120

SCRIPT FOR SHOWS WITHOUT ANCHOR/PRESENTER

#### "JULIO AND JORGE - BEYOND THE LABYRINTH

#### **ANNOUNCEMENT**

Coming up on 21<sup>st</sup> Century (2")

Julio and Jorge Beyond the Labyrinth. (3")

#### **VIDEO INTRO:**

#### **NARRATION**

From THIS ... (images of Julio in cell) .... to this .....(images of Julio playing with blanket, etc). From THIS ... (Jorge at cell window) ... to this ... (images of Jorge lying on bed next to sister). In Paraguay, the long road to freedom for two people with disabilities. (19")

#### **MARTIN MORENO:**

No existen porque estan invisibilizado. Es un tipo de violencia social.

They don't exist, because they are made invisible. It's a kind of social violence. (7")

#### **NARRATION**

But when rights are respected, there can be remarkable progress. (4")

#### BLACIDA:

I've been living with the guilt of putting my son in there – but he came back and, for me, that was the absolute best. (11")

#### **NARRATION**

The parallel lives of Julio and Jorge, filmed over decades (7")

### PARAGUAY: "JULIO AND JORGE – BEYOND THE LABYRINTH" (22'53")

<u>VIDEO</u> <u>AUDIO</u>

NAT SOT

SEQUENCE OF JULIO IN CELL, NAKED; HE WAKES UP

<u>NARRATION</u>

JULIO IN CELL; LOOKING THROUGH BARS

In 2008, we travelled to Paraguay and shot these images with Julio Rotelo. Despite having committed no crime, he had spent the last fifteen years of his young life behind bars, often in solitary confinement. They were some of the most disturbing scenes I had ever witnessed.

STILL BLACK AND WHITE PHOTO OF JULIO

NAT SOT

(31")

STILLS OF JORGE; JORGE

<u>NARRATION</u>

BEHIND BARS;

We also met Jorge Bernal, close in age to Julio, and sharing a similar, little-understood disability. For several years, they were incarcerated side by side in the state's psychiatric institution (17")

JULIO IN CELL EATS CRUMBS FROM FLOOR;

JORGE IN CELL IN INSTITUTION

Both young men have a severe form of autism, an intellectual disability. And they both suffered at the hands of a society that failed to understand and to protect them – which locked them behind bars, treating them with fear rather

STILL OF JULIO BEHIND

BARS

than compassion. (18")

SPLIT SCREEN IMAGES OF BOYS

But their stories began some three decades earlier. (3")

#### MUSIC

JULIO (AGED 7) BEHIND FENCE

SINFOROSA BUILDING A FIRE

Abandoned as a baby, Julio's grandmother was left to raise the severely mentally-disabled two-year old. (7")

NAME SUPER: Sinforosa Dominguez

SINFOROSA ON CAMERA

SINFOROSA DOMINGUEZ: (In Guarani) **F**"I loved him very much, I saw him grow but I
suffered a lot during that time when he had his
attacks. One day he fell in the bath and crashed
his head. Things were always happening to him
...." (18")

# SINFOROSA IN THE KITCHEN

#### **NARRATION**

Alone and struggling to cope, she resorted to tying Julio to a tree to keep him from escaping. (6")

FOOTAGE OF JULIO AT SEVEN YEARS OLD.

PHOTOS OF JULIO WITH NURSE, LUCILA CONTRERAS At seven years old, Julio was taken away from her. With no other facilities available in this, one of the poorest countries in Latin America, he was put into the state's only psychiatric hospital in the capital, Asuncion. At first, funds were set aside for his individual care by a dedicated nurse, as seen in this footage shot at that time. (23")

LUCILA CONTRERAS ON CAMERA NAME SUPER: Lucila Contreras

**FOOTAGE OF YOUNG** 

LUCILA CONTRERAS: (In Spanish) **F**"He was such a tense boy, hyperactive, he'd cry,
he'd shout, he used to break everything, he used
to hit himself against the wall ...When he used to

#### JULIO WITH LUCILA

run to a corner shouting and crying, I'd say
"Come here, Juli, my baby, come here to my
arms" and he'd come and put his head on my
lap and he'd calm down. I would stroke his head
and pet him until he was calm. We'd spend
hours like that..."(25)

LUCILA KISSING YOUNG JULIO

#### **NARRATION**

For a year, she looked after just him. (2")

BCU JULIO'S FACE THROUGH FENCE

#### LUCILA CONTRERAS (In Spanish)

"He used to look me in the face and started to say Ma, Ma – mama. "(4.5")

#### **NARRATION**

MALE NURSE LEADS JULIO INSIDE THE INSTITUTION

When the funding ran out, everything changed. He was taken from Lucila and put into the men's section where, for his own safety, he was locked up alone. (10")

#### JORGE WITH BLACIDA; SILHOUETTE-SHOT OF JORGE PLAYING WITH HIS HAND

#### **NARRATION**

Jorge Bernal's story began in another poor house-hold in Asuncion. As an autistic child, he was always running away from home. Receiving no help for his care, when his young mother gave birth to her sixth child, she struggled to manage him. (16")

BLACIDA AREVALO ON CAMERA

NAME SUPER: Blacida Arevalo

BLACIDA AREVALO (In Spanish) F

My baby, Natalia, was just born. And lots of times, I had to just leave her to go and look for him... At 5 in the morning, at midnight..." (15")

#### **BLACIDA SWEEPING**

#### **NARRATION**

In desperation, she turned to the authorities.

The only solution, they told her, was to put Jorge in the institution. (8")

#### **BLACIDA ON CAMERA**

#### BLACIDA AREVALO: (In Spanish) F

"They told me there was no help available but that I could go and visit him when I wanted. Because your son is never going to be useful to society, they said." (13")

#### **NARRATION**

#### 2003 FOOTAGE - MAN LIES ON GROUND IN INSTITUTION

In 1996, 12 year old Jorge was also admitted to the Neuro-Psychiatric Hospital, and put in the cell next to Julio. For 23 hours a day, they were locked away alone, in filthy, cramped cells – neighbours in their isolation. (16")

JORGE BEHIND BARS IN CELL; JULIO LYING ON FLOOR IN CELL;

#### CU JORGE THROUGH BARS

### BLACIDA AREVALO (In Spanish) F

And I asked them, why do you shut him up?
The more you shut him away, the worse he's
going to get! (7")

STAFF AT INSTITUTION AND LAWYERS OUTSIDE JORGE'S CELL;

#### **NARRATION**

This is where human rights lawyer, Alison Hillman, found them in 2003. She shot this footage of them. (8")

MS ALISON HILLMAN WITH MAN

INPATIENT URINATES ON FLOOR;

INPATIENT DRINKS FROM POOL OF WATER ON GROUND; JULIO DRAGGED BY A NURSE ALISON HILLMAN: (In English) F

"They slept and ate and resided in the very same space where they defecated and urinated. They were taken out of their cells to be hosed off.... (10")

ALISON HILLMAN ON CAMERA

NAME SUPER: Alison Hillman

**BCU MAN'S BANDAGED** FOOT: JULIO NAKED, LED AWAY BY NURSE

ALISON HILLMAN ON CAMERA

ALISON HILLMAN: F (In English) when you have a locked institution, whether it's an orphanage or a psychiatric hospital or a prison ward, you find abuse, neglect, children

from society, they're really invisible (18")

tied to beds. When people are locked away

SUPERIMPOSITION -BARS, POOLS OF WATER ON GROUND: CORRIDOR IN INSTITUTION -DISSOLVE THROUGH TO NO BARS

PARAGUAY FLAG: **EXT PARLIAMENT** BUILDING, ASUNCION, PARAGUAY

EXT UN HEADQUARTERS, **NEW YORK** 

UN GENERAL ASSEMBLY

REPRESENTATIVE FROM **PARAGUAY SIGNS** CONVENTION

**NARRATION** 

In response to Alison's unveiling of the violations being committed and a subsequent ruling by the Inter-American Commission on Human Rights, the conditions in the state-run psychiatric hospital improved slightly.

And in 2008, Paraguay ratified the United Nations Convention on the Rights of Persons with Disabilities (23")

NAT SOT: The Republic of Paraguay...

which recognizes the right of everyone to live in dignity. (3")

2008 FOOTAGE - JULIO IN **ROOM IN INSTITUTION** 

A few weeks' later, I went to Paraguay with Alison to see what had changed in Jorge and Julio's lives. Julio had been moved to a separate space in the institution for autistic boys.(12")

ALISON ON CAMERA IN JULIO'S ROOM

ALISON HILLMAN (in English)

This cell is a bit larger, it's a bit cleaner. And he does have access to a bathroom but I don't believe that he has learnt how to use it. (9.5")

FOOTAGE OF JULIO TUGGING HIS BLANKET WITH HIS NURSE. BCU JULIO REACHES THROUGH THE BARS OF HIS CELL; NURSE FEEDS JULIO THROUGH BARS OF CELL:

#### Nat sot

#### ALISON HILLMAN (In English) F

"That's what the international convention stipulates - that people with disabilities have the right to be in the community and to receive the services and support that they need to live in the community."(10")

### ALISON HILLMAN ON CAMERA

"I think that at this point there is will, on the part of the government, to change Julio's conditions and to get him into a substitute family-like setting but I think that mostly it's been a lack of resources and a lack of knowing what to do." (14")

2008 FOOTAGE – JULIO DRAWS WITH HIS SISTER, NATALIA 2008 – JORGE WITH HIS MOTHER, BLACIDA, AT HOME;

#### MUSIC

#### **NARRATION**

In 2008, Jorge's life had, in contrast, taken a different path. His 9 year stay in the institution had ended a year earlier. Because Blacida had found a cleaner's job and her other children were now older – she was finally able to take him back home. (17"

JORGE AT TABLE WITH FAMILY EATING

**BLACIDA AREVALO ON** 

BLACIDA AREVALO (In Spanish) F

I feel really good because it's like it was before
... I've been living with the guilt of having put my

CAMERA

son in there. But he came back, and for me, that was the absolute best! (16")

JORGE WITH BLACIDA AND BROTHER, GET OFF BUS; WALKING

**NARRATION** 

Jorge found himself at the centre of a doting family and blossomed, relearning the social skills he lost during his years in isolation, as this footage shows. (15")

JORGE DANCES WITH YOUNGER BROTHER; THEY LIE TOGETHER ON THE FLOOR LAUGHING, PLAYING

MUSIC (nat sot RADIO)

2016 FOOTAGE - PLANE TAKING OFF SHOTS

BCU PARAGUAY FLAG; WS ASUNCION SKYLINE; GV BUSY STREET ASUNCION

In 2016, we went back to Paraguay for an update on Julio and Jorge's parallel lives. (6")

JORGE'S HOME – WASHING; JORGE SITS IN CHAIR, BLACIDA SWEEPS Jorge, now 30, was still living with his family. (4")

BCU JORGE PLAYS WITH HAND

BLACIDA AREVALO ON CAMERA:

BLACIDA AREVALO (In Spanish) F

He's the priority. I'm always aware of how lucky I am to have so many children, because they help me with everything in caring for Jorge. (12")

BLACIDA AND NATALIA PUT TALCUM POWDER ON JORGE:

THEY PUT T-SHIRT ON

JORGE;

BCU MEAT ON BBQ; BROTHER COOKING; **NARRATION** 

There is still no state financial or social help at all for families with a disabled member, so Blacida's children share the responsibility for Jorge's care with their mother. Natalia, now 19,

NATALIA KISSES BLACIDA

explains when she is able to go to school. (23")

#### NATALIA ON CAM

NATALIA (in Spanish) F

Friday nights, Saturday at noon and Sunday mornings, because other days, I need to look after Jorge. (11")

#### NATALIA AND JORGE LYING ON THE BED

#### **MUSIC**

#### BLACIDA (in Spanish) F

She makes this sacrifice to stay with him. And she's the one who understands him best – or understands him totally. (10")

#### **NARRATION**

## EXT IN PSYCHIATRIC INSTITUTION;

While Natalia is with Jorge, Blacida earns the money for the family.

### BLACIDA CLEANING AT THE INSTITUTION

As in 2008, she still works as a cleaner at the same institution where both her son and Julio were once locked up. (12")

#### BLACIDA (In Spanish) F

They employed me to help me, so that I could take care of my son, so that he had food to eat, and everything. (6")

### SEQUENCE OF STILLS OF JORGE

#### **MUSIC**

#### **NARRATION**

And she's more grateful now than ever to have a job (5")

#### **BLACIDA**

A year ago, he developed a disease – diabetes – brought on by all the medication he was taking for his condition. It was really difficult for us, at first, because his moods would change, he didn't sleep and, often he would cry and we didn't know why. (25")

**BLACIDA ON CAMERA** 

#### **BLACIDA AREVALO**

We spent almost a year like that until a doctor decided to try this other medication. (9")

#### **BLACIDA AREVALO**

BLACIDA IN THE GARDEN WITH JORGE

And I pay for his medication because the State has no programme for this. (10")

BLACIDA CLEANING FLOORS

#### **NARRATION**

Finding a better-paid job would certainly help. And Blacida feels she could do more than just clean the floors. (8")

BLACIDA TALKS WITH PATIENT IN THE INSTITUTION

#### **BLACIDA**

I would like to spend time with the patients in the workshops, to play with them, interact with them. Many times, I understand them, we have small achievements – it's really special. At times, it makes me think of.. that this is from Jorge! (17")

BLACIDA WALKING ALONG RURAL ROAD; CATCHES BUS

#### **NARRATION**

And now, thanks largely to years sharing her life with Jorge, she has a plan for their future. (6")

#### **BLACIDA**

**BLACIDA GOING TO** 

**EVENING CLASS AT** UNIVERSITY

**BLACIDA ON CAMERA** 

WS CLASSROOM

I'm studying psychology. I decided this because I like it and, in my case, it will allow me to spend more time with Jorge and understand him better.

(16")

STUDENTS AND BLACIDA IN CLASSROOM

**BLACIDA** 

He also teaches me many things. But my studies are more so that I'll be able to give him a

better life. (6")

EXT COMMUNITY HOUSE, LIMPIO, PARAGUAY; JULIO SITS ON BLANKET ON FLOOR

<u>NARRATION</u>

And for Julio, now 31, life has already taken a turn for the better ...(6")

DR MARTIN MORENO ON CAMERA

DR MARTIN MORENO (in Spanish) M

This is a "substitute home". It has the function of a transit place. Some residents find their families and return home. In this specific house,

it's not the case. (9")

Dr MORENO PLAYS GUITAR NAT SOT MUSIC AND PATIENT SINGS

NAME SUPER: Dr Martin Moreno **DR MARTIN MORENO** 

I'm a psychiatrist, a psychotherapist and I work in the area of substitute homes, for the Mental

Health department. (10")

DR MORENO AND PATIENT PLAYING GUITAR

SINGING

JULIO ON BLANKET ON **FLOOR** 

DR MARTIN MORENO

I've known Julio since around 2003. I didn't have a direct relationship but I knew he was

locked up along with Jorge. (14")

**CLOSE UPS OF JULIO** 

JULIO PLAYS WITH BLANKET; BARS OF CELL; Julio is better than when he was in the hospital. Here he has a vision of the horizon. In the hospital, his vision was fragmented by the bars. He has space to go out and walk around. In the hospital, his space was much smaller. And he used to tear cloth/materials, which was a way of expressing his anxiety, his fury. "What rage I feel! What impotence!" (36")

2008 FOOTAGE – JULIO TEARS CLOTH

JULIO TEARING CLOTHES

He was like a child trapped in a labyrinth. (3")

JULIO WITH OTHER
PATIENTS IN COMMUNITY
HOUSE; CARER DRESSES
JULIO;

Now he bonds with people – he watches, he looks into your eyes and he is able to maintain his clothes intact, to maintain a pattern in his behavior with a time for sleeping, a time for playing, a time for eating. And now he doesn't break cloth, but plays with it. (25")

JULIO PLAYING WITH HIS CLOTH

It's like an intermediary object of communication, which says "here I am". (5")

OTHER PATIENT PLAYS WITH BALL WITH JULIO;

What has saved him is the bond he has with his house-mates. You could say that they are Julio's family. And many of them are responsible for the ties he has. And you say "But these are sick people who are making these bonds". But if you don't look at the illness, what is left is the bond, the closeness. (23")

JULIO HOLDS MAN'S HAND

He's like the child in the family, the smallest, the most vulnerable. (5")

JULIO WITH HIS BLANKET IN HIS ROOM

**NARRATION** 

But Julio's is one case – is enough being done? (4")

#### **DR MARTIN MORENO**

BOY THROUGH BARS INSIDE INSTITUTION; MAN LIES ON GROUND IN INSTITUTION: There are many more... many who are invisible in this predicament. They don't exist because they are MADE invisible. It's a type of social violence. On the one hand, there's the stigma the parents feel for bringing a defective child into the world, and on the other, how the State fails to acknowledge that they exist. (22")

CATALINA DEVANDAS OUTSIDE UN BUILDING, GENEVA

#### **NARRATION**

According to the United Nations appointed independent expert who visited Paraguay in 2015, progress has since been made but there are still many gaps. (11")

#### NAME SUPER:

Catalina Devandas, Special Rapporteur on the Rights of Persons with Disabilities

2003 FOOTAGE – JULIO AS A BOY BEHIND FENCE CATALINA DEVANDAS (In English) F

There are no support services in Paraguay for children or for, in general, people with intellectual disabilities. //

Autistic children are being absolutely discriminated, they face enormous and grave violations of their rights, even in the most developed countries so I couldn't say that Paraguay is a unique case. (21")

2016 FOOTAGE – PSYCHIATRIC INSTITUTION, ASUNCION

In most cases what happens is that they have no resources and adequate support services, so they might end up locked up in a psychiatric facility which is totally unacceptable (12")

### EXT MINISTRY OF HEALTH, ASUNCION

NAME SUPER: Dr Mirta Mendoza, Director of Mental Health, Ministry of Health

#### DR MIRTA MENDOZA (in Spanish) F

The issue is always the budget. There isn't any specific Mental Health legislation. If there was a Law, they would have to allocate a budget. (12")

#### DR MENDOZA ON CAMERA

INT PSYCHIATRIC INSTITUTION, ASUNCION

I think that here in our country, there's a policy of investing in hospitals as a means of addressing health – not in prevention, nor in rehabilitation – these are still not properly developed. (17")

DR MENDOZA ON CAMERA

# INSIDE PSYCHIATRIC INSTITUTION, ASUNCION

#### **NARRATION**

The medical director at the psychiatric hospital disagrees. There HAVE been advances, he says. (7")

#### DR ADORNO ON CAMERA

#### NAME SUPER: Dr Victor Adorno, Medical Director, Psychiatric Hospital

CU WOMAN EMBROIDERING; GARDEN IN PSYCHIATRIC INSTITUTION; PATIENTS DOING HANDIWORK IN INSTITUTION

#### DR VICTOR ADORNO (in English) (M)

We have a department of rehabilitation for our patients where they do art, craftwork // They do physical activities, they also have a place to plant. // We emphasise their rehabilitation. // Our objective in the long term is for the long-staying patients to be in a house, not in the hospital, not behind bars — somewhere comfortable, somewhere where they are able to develop their abilities ... (30")

#### CATALINA ON CAMERA

# PATIENTS INSIDE INSTITUTION

#### CATALINA DEVANDAS (in English) F

The situation has changed, but it's still not adequate. A lot of people are detained there in the psychiatric hospital. Despite the efforts by local authorities and by the staff in the hospital, the conditions remain very dramatic in the

#### hospital. (20"

JULIO'S OLD CELL IN INSTITUTION; PATIENTS INSIDE INSTITUTION; 2007 FOOTAGE – JULIO INSIDE CELL

#### <u>NARRATION</u>

Although Julio's cell now lies empty of inmates, some 150 patients in the hospital are still awaiting their chance of a different life. (9")

And Dr Moreno feels Julio's life could have been transformed had his needs been recognized earlier ... (6")

DR MORENO ON CAMERA

2007 FOOTAGE - BCU JULIO THROUGH FENCE DR MARTIN MORENO (in Spanish) M

If there had been a systematic practice of work back in 2003, more integrated and continuous, then perhaps he would have had different opportunities. I'm not saying he would have

been cured, but he may have been able to

function better.. (21")

2007 FOOTAGE – CU JORGE BEHIND BARS WITH MUG

<u>NARRATION</u>

Blacida feels Jorge would also have benefitted

from different treatment as a child (4")

**BLACIDA ON CAMERA** 

BLACIDA

STILLS OF JORGE

When he was very small, 2 or 3 years old, he would babble a few words and then later he lost them. But we didn't know anything! There was no centre or anything, and, even less, any help. I think that if the state had given us some real help, I wouldn't have done many things. We wouldn't have gone through what we went through, and he would have been saved from all

**BLACIDA ON CAMERA** 

those years of internment, and things would

have turned out differently ...(33")

# JORGE IN THE GARDEN WITH HIS FAMILY

#### <u>NARRATION</u>

Jorge's future now rests solely in his family's hands. As long as they are able and willing to look after him, his care is assured. (9")

Meanwhile, Dr Moreno sums up what lies ahead for Julio. (8")

## JULIO IN THE COMMUNITY HOUSE

#### **DR MARTIN MORENO**

He's a child of the state. I think that in the future, he will be looked after until the end of his days. But he stays here, where he's now made his roots. (12")

# STILLS OF JORGE AND JULIO

#### CATALINA DEVANDAS (In English) F

Disability is part of human diversity and we should just deal with the social factors that allow the interaction of these people on an equal basis with others - how to make sure we have equal opportunities to participate and how to accommodate a society that was designed for people without disabilities - and that's our fight (19")

# CATALINA DEVANDAS ON CAMERA

#### STILL OF BLACIDA AND JULIO; STILLS OF JULIO AND JORGE

#### **NARRATION**

The story of Julio and Jorge shows that though the struggle continues, with support and respect, there is hope. (9") (TRT 22'53")

#### **LOOK AHEAD**

Coming up on a future edition of 21st century

DRONE SHOTS OF VINEYARDS
ANDES MOUNTAIN RANGE
MENDOZA
DOMINIO DEL PLATA

GENERAL VIEW OF VINEYARD
GRAPES

#### **NARRATION**

Sitting at the foot of the Andes Mountains in the western part of Argentina, the vineyards of Mendoza province produce some 70 percent of the country's wines – a multi-million dollar industry representing 1.3% of the country's gross domestic product. (17")

But the brunt of climate change may have an impact on water supplies in Mendoza because of melting glaciers and less snow capped mountains, putting pressure on wineries. (10")

BALBO: (In Spanish)

"The adjustment to the lack of this resource is something that we owe to our children. So we looked into a different method of irrigation - drip irrigation – which delivers just the right amount of water that the plants need without wasting water." (16")

### **CREDITS (30")**

### 21<sup>st</sup> Century

#### A production of

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Department of Public Information

# Julio and Jorge: Beyond the Labyrinth

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