CAPABILITY ARGENTINA

CHACO Outreach Project

The Development of a Primary Health Care- Based Medical Genetic Service in an Argentinean Province.
Education for health care professionals: tool for Capacity Building ***in Chaco***

REPORT DEMONSTRATION PROJECT PARTNER 7
2007-2009

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A Brief Background of the CAPABILITY Project Argentina:

The advances and dissemination of genetics to be applied in medicine have created a growing need for capacity building in health care workers. This capacity building should be aimed at the development of competency in the field of genetics allowing health care workers to familiarize with new technology and concepts. The development of a capacity building network would stimulate the design of new programs in public health to promote better health care and disease prevention. In this report, we present the most relevant steps taken in this process between January 2007 and December 2009.

Our aim was for genetic health care to become part of primary care in the Argentine province of Chaco through capacity building in genetics.
Medical genetic services, as in almost all middle income countries, are not universally available in Argentina, being mostly urban centred, mainly in the city Buenos Aires and surroundings. These services are heterogeneous and in majority incomplete, usually counting on only one geneticist or only one laboratory, generally for cytogenetics, which is why systematization and integration in a network is fundamental and imperative.

Chaco is one of the 10 provinces in Argentina lacking genetic services, located in the north-east of the country. Chaco has 1,042,881 inhabitants.
The province is located at a distance of 1130 km from the City of Buenos Aires, the home of our institution (Garrahan Hospital S.A.M.I.C.).

As to the logical framework for the planning of these processes, we used the following work strategies:

- Teaching strategies and educational material for distance education.
- Teaching strategies and educational material that are useful for capacity building in centres where the work is intensive (hospitals/health care centres) and where hands-on experience is the starting point of learning.
- Strategies that encourage the building of a working network based on hierarchical responsibilities facilitating consultations with specialists and avoiding work in an isolated fashion (Many institutions like islands = Paradigm of the archipelago).
- Strategies that allow for continuous education and permanent training as a tool for the improvement of primary care and fast dissemination of knowledge in this area.
- Strategies that favour the amplification effect: training new teachers.
- Strategies that favour the participation of different social entities; among others, the participation and commitment of national and local authorities (National Ministry of Health and Ministry of Health in Chaco) as well as national and local health care workers. It is important to emphasize that this project aims at preserving and encouraging local, native knowledge, language diversity, and local societies that offer cultural factors and basic knowledge for the implementation and development of the program. On the other hand, the

announcement of the initiation of the CAPABILITY project in the province of Chaco in the local media gave rise to high expectations in the local health care team (political effect).

- In our courses in genetic competency and skills for the health care team working with ethnically diverse patient populations we used the PRACTICE mnemonic (prevalence, risk, attitude, communication, testing, investigation, consent, empowerment) to help health care professionals integrate cultural competency skills in genetics into primary care.

PRACTICE Mnemonic for Integrating Cultural Competency into Genetics Teaching and Clinical Care (from Reynolds, et all)

Prevalence	Prevalence of the disease in the population, and known statistics about ethnic and racial disparities in disease prevalence and mortality
Risk	Risk that a disease has a genetic basis
Attitude	Attitudes of physicians and patients and how these influence the delivery of genetic services
Communication	Communication bridges and barriers with attention to the use of schematic illustrations and interpreters for difficult to understand concepts
Testing	Testing with reference to sensitivity and specificity and positive predictive value of genetic testing for a specific disorder
Investigation	Investigation of the family history focusing on clues for inherited disorders; discussion on how culture influences available family history information
Consent	Consent for testing and whether there are cultural preferences for oral versus written consent; and exploration of who makes decisions and who keeps medical information within families
Empowerment	Empowerment of the patient to take ownership of the decision whether or not to undergo genetic testing

As the authors say “The importance of cultural competency in health care has been well documented and discussed in the contemporary literature. The importance of cultural competency in genetic education is outlined above and applied in the PRACTICE mnemonic which provides a systematic tool for discussion of a general medical case and allows for the inclusion of evidence based teaching in the education of medical students”.

Background of CHACO as the province for implementing the Demonstration Project Argentina:

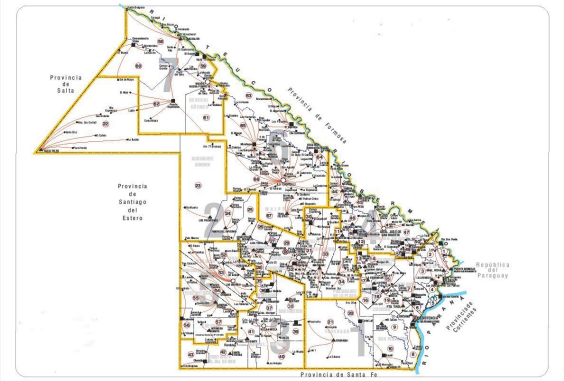
Why was the province of Chaco chosen as the venue for the demonstration project? Major points for the choice of Chaco as a model for implementing the demonstration project:

1. The health organisation in Chaco:

- Absence of genetic services in that province.
- Presence and distribution of Distance Communication offices: Until the first semester of 2009, Chaco was divided into 6 Sanitary Areas and each sanitary area has had a Distance Communication Office (**DCO**) since the end of 2006, which has been connecting health care professionals of Chaco with our institution. The **DCO** is an excellent tool to strengthen ties between Chaco and a tertiary care centre for the diffusion of educational material, the technical organisation of courses with the attendance of pupils, and, fundamentally, consultation and referral of patients. The strategic distribution of the DCOs allows for a better approach and coverage of the whole province.
- Recently, the 6th zone has been subdivided into 2. Today the province has 7 Sanitary Zones, and in each sanitary zone there are different districts. There are 400 well-staffed health care facilities in the entire province. This health care network is structured on the basis of an outline zoning plan which considers: accessibility and coverage based on health needs; the circulation and natural reference population, the phasing in of the complexity levels of services, the provincial road network. Three are provincial referral centres (tertiary care) belonging to Sanitary Areas I and II and 110 secondary care facilities. The remaining facilities are small primary care centres located in remote places, staffed by nurses and with scheduled visits by medical professionals.

LEVEL OF COMPLEXITY	TYPE OF CENTRE	QUANTITY
I	Primary care centres "B" (Rural)	264
II	Primary care centres "A"	29
III	General Hospitals	36
IV	Hospitales Zonales (SP, VA, GSM, LB, JJC)	5
VI	Interzone Hospitals (Sáenz Peña)	1
VII	Provincial Hospitals	2
III	Urban Health Care Centres	63
TOTAL	Total	400

Chaco Province: Seven Sanitary Zones



Note: Primary Care Centres and how they work

Primary Care Centres A
Work schedule: Both physicians and nurses in this type of centres work 44 hours a week . Physicians do on-call duties while nurses do active duties.

Primary Care Centres B
Work schedule: Physicians visit the centres to meet scheduled appointments. Times differ according to the place where the centre is located. In the absence of the physicians, the centre is staffed by nurses who work approximately 33 hours weekly. Activities developed in the centres are out-patient visits, home visits, census activities, and citation of patients.

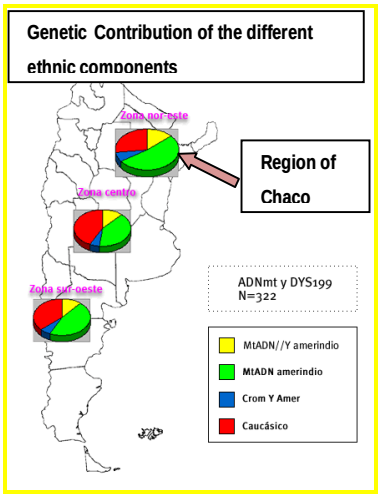
In this context it was of utmost importance to include the whole health care team in the training program.

2. Human resources in Chaco:

Before this project, we had worked with a group of highly trained professionals in Chaco. Thus, in 2007, we got in touch with these professionals working in the main paediatric Hospital of the capital of the Province (Resistencia City, in Sanitary Zone I, Castellans Hospital) and we incorporated human resources from the town of Resistencia in order to set up the local team (paediatricians, a communication technician, and a management technician). This local working group has worked in Chaco in coordination with the source team (Garrahan team). This point will be further explained in the last section of the report.

3. Social and geographic conditions make endogamy a possible risk factor:

- There are closed groups: a) Native populations (about 50,000 inhabitants belong to Toba, Wichi, and Mocoví communities) b) European immigrants, distributed over 8,300 communities (accounting for 7.96% of the population of the province while in the whole country they represent 4.21 % of the population).
- Areas of very difficult access: Rainforest "El Impenetrable" which is located in Sanitary Zone VI.



Reference:

In yellow: Mitochondrial DNA and Y Cr of natives

In green: Mitochondrial DNA of natives

In blue: Y Cr of natives

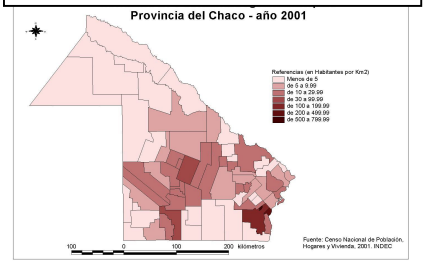
In red: Caucasian DNA

Picture adapted from: Impacto de las contribuciones genéticas de los diversos grupos étnicos en la población actual del país. Corach D, Sala A and Marino M. Educar portal educativo del Estado Argentino 06/06/2008

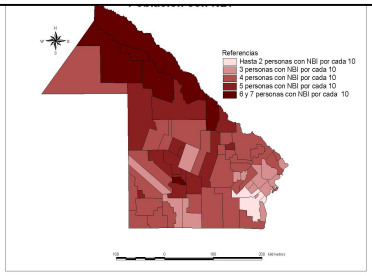
4. Social, political, and economic conditions cause the impact of genetic factors to increase:

Unsatisfied basic needs are higher than 30% and infant mortality is estimated at 19.7 ‰ .

Population density by district. Reference: Greater density in dark pink



Unsatisfied basic needs in the population. Reference: Population with the higher needs in dark pink



5. **Access to graduate and post-graduate training of members of the health care team:**

Graduate training of technicians, medical doctors, and other health care professionals take place at the Nor east University in the province of Corrientes (bordering with Chaco)

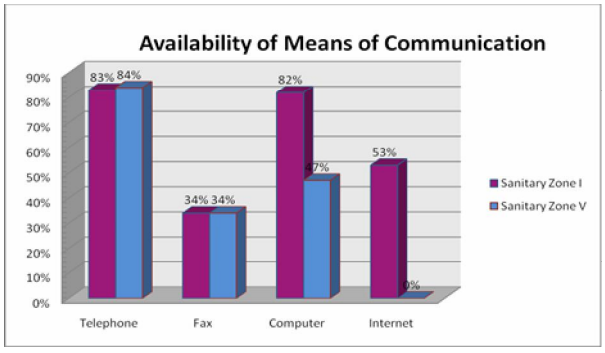
Specialization and post-graduate education depend on:

a) Access to residency programs
b) Presence/absence of departments of research and development in provincial hospitals.
c) Post-graduate courses generally are given in Buenos Aires (at a distance of 1130 km), nearby provinces (Corrientes and Córdoba), or only in the capital of the province of Chaco.
d) Access to an internet connection and/or PC.

As to points a-b, and related to the training project of CAPABILITY Argentina:

Sanitary Zone and Health Facilities (HF)	Main Hospitals	Department of Research and Development	Residency Programs	WORKSHOP CAPABILITY Training program DONE
I 93 HF	- Hospital Pediátrico "Dr. Avelino L. Castelán - Hospital "Dr. Julio C. Perrando	Yes Yes	All specialties	Yes
II 77 HF	Hospital 4 de Junio "Dr. Ramón Carrillo	Yes	Paediatrics	Yes
III 29 HF	Hospital Salvador Mazza	No	General Medicine	No
IV 41 HF	Hospital Felix A. Pertile	No	General Medicine	No
V 39 HF	Hospital 9 de Julio	No	General Medicine Rural Medicine	Yes
VI y VII 121 HF	Hospital Gral. Güemes (Sanitary Zone VI)	No	Rural Medicine	Yes

As to point c, taking into account these limitations, the training symposia were not held in the capital of Resistencia, but were started in the interior of the province (Sanitary Zone V Las Breñas), and afterwards continued in Sanitary Zone I , Sanitary Zone II, and finally in Sanitary Zone VI so as to cover different areas throughout the province. Evaluation of point d has been a limiting factor in the financial distribution and the design of resources in the development of the CAPABILITY project.



Study materials (Syllabus) were printed for each of the pupils of each Sanitary Zones who also received a CD. This implied a higher cost.

Figures of the CAPABILITY Argentina Survey:

Comparison of the results in the area of the provincial capital (Sanitary Zone I) and the smallest area where the training program was developed (Sanitary Zone V)

In Sanitary Zone V:
(Where the Demonstration Project was started)

All institutions lack Internet connections.
Web page access is limited to the home of only a few professionals.
Only 47% of the health centers have a PC.

Strategic Planning Phase:

Mission: To develop capacities in genetics to apply in primary care, to familiarize health care professionals with new technologies and concepts according to the nature of their socio-economic environment. To formulate, plan, and evaluate policies and strategies addressed towards continuous development of knowledge in genetics and the search for excellence in said activities.

Vision: To be a national leader in the development and carrying out of education-learning processes; effective use of technology and application of clinical processes to improve quality of care and follow-up of patients in their place of origin through the training of human resources necessary for teaching and patient care.

General focus: To establish objectives, to evaluate the socio-economic environment in the target area, to adapt to specifications and plans of interested sectors to achieve a common vision. To analyse preliminary results and improve and modify in the course of the project (Continuous Process Improvement).

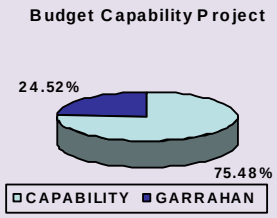
General Objective: Design and implement a model of local delivery (Demonstration Project CAPABILITY Argentina) taking into account the particular characteristics of the selected area as a field of implementation in correlation with the recommendations of the Needs Assessment Argentina.

Specific objectives:

- To design a strategic framework for the organisation of a demonstration project taking into account the recommendations for Argentina and specific features of the province to be selected using the health care team as a tool to train professionals.
- To present a logical framework as shown to the other participants of the Consortium at the CAPABILITY meeting in Seville.
- To present the logical framework to national and provincial health care policy makers so as to obtain permission to implement the protocol and involve them in the management process of the project.
- To start the demonstration project in the Province of Chaco so as to generate the capacity for the coverage of genetic health care in a province that lacked the service.
- To integrate the following stakeholders in the demonstration project: members of the health care team who work in primary care, geneticists, university teachers (university), health institutions of different levels of complexity, parent associations, the media, political and sanitary authorities.
- To analyze the results of the pilot experience of the Demonstration Project (in Sanitary Zone V: Las Breñas, Chaco).
- To make necessary modifications to improve implementation in the remaining Sanitary Zones (results management, continuous process improvement).
- Progressively integrate community in objectives and design of activities.
- To continue activities in each of the remaining sanitary zones: a) survey of human and institutional resources and previous knowledge, b) capacity training in seminars (beginners training level); c) update of the web page (continuous update training level), d) Program of training of teachers (amplification training level).

- To disseminate the results of the project to the national and international scientific community.
- To write a procedures manual.
- To sustain the accomplished structure in the province and to amplify the initial effect so as to continue the work once the CAPABILITY protocol has finished.
- To encourage complementary projects financed in Argentina, to reproduce the model in other areas in the country, and to continue the work in Chaco.

Logical Framework: CAPABILITY ARGENTINA:

CAPABILITY ARGENTINA	**OVI: Objective Verification Indicators**	**MOV: Means of Verification**	**HYPOTHESIS**
Aim: To create genetic services in primary care in the province of Chaco	The population of the province of Chaco has access to genetic services	Statistical data of the Ministry of Public Health of the Chaco Province Report of the results of Capability	There are no clinical genetic services available for patients in the province.
Purpose/ General aim: Capacity building in basic genetics for health care workers in primary care with ongoing updates through a Specialized Reference Center **(SRC)**	**By December 2009**. The **HCP** will have received basic knowledge on genetics that allows them: To locally resolve the most common pathologies (diagnosis, follow-up, counseling).To consult and refer the patient to a specialist at an early stage	**Deliverables: report 2007-2009** Reason and number of consults, risk factors detected, diagnoses found, number of genetic counseling, number of patients referred	The increase of knowledge in the field of genetics and the lack of transmission of this knowledge to **HCPs**, added to the difficult access to a nearby hospital with a department of genetics lead to the absence of genetic services for patients. Training in basic principles of genetics applied and adapted to local practice will improve this situation.
Components: • **Initial formation**: Training of health care professionals working at health centers in different sanitary areas in Chaco in genetics • **Continuous education** Communication to achieve periodic updates for the HCPs to improve the quality of attention. • **Amplifying effect** Training of new teachers	**At the end of the second semester of 2009**: The HCPs have participated in the initial capacity-building activities: seminars, workshops and teaching consults. Each health care centre has received basic study material. **For December 2009:** In the province of Chaco, the HCPs will: interconsult with local specialists who are part of the network of specialists (SRC) teleconference / Serv. COMDIS The HCPs and pupils will be able to use the web page of Capability Argentina. **When finalizing**: Formation of training continued and the model will be reproduce in other provinces	Register of **HCP** in the province of Chaco Register of health care centers Forms of participation in the workshop Forms of participation in the Teaching Consults Forms of receipt of teaching materials Number of teleconferences with participation of the province of Chaco Number of referrals to SRC Number of counter referrals to Chaco Number of visitors and consults to the web page	Availability of teachers from the **SRC** to teach in the workshops Availability of time for participation in the workshop Availability:-of the department and the personnel of distant communication in Buenos Aires and in Resistencia, Chaco.-of local specialists for referrals-of medical staff at the **SRC** for update of the web page. Political support for the amplification of the model: by means of the recognition of the project and the importance of forming new educational agents.
Activities: • Training courses in the sanitary regions • Teleconferences and web page: updates • To transfer contents agreed to the profile (to see contents) in the SRC, to maintain connections with the SRC for update	**Costs/Preliminary estimate** 	**Receipts of expenses** **Annex II Formulary C**	

S.W.O.T. matrix analysis:

Results Management (continuous process improvement)

	Positive	Negative
Internal Factors	**Strengths** ○ S1 High-level national service supported by authorities and personnel of the Hospital to improve on-site patient care. ○ S2 Interdisciplinary human resources have formed a working and managing group to establish change. ○ S3 Experience of human resources in administrative, patient-care, teaching, managing, and technical areas to implement the processes to meet the objectives proposed by the project. ○ S4 Special and new features of the product offered	**Weaknesses** ○ W1 Closed funding of the project without foreseeing the fast development and need for new investment. ○ W2 Paediatric orientation of the service does not include a team for prenatal diagnosis ○ W3 Hospital bureaucracy delays project planning ○ W4 Initial asymmetry of information. ○ W5 First experience with coordination of an Argentine intra-institutional, extra-institutional and international project.
External factors	**Opportunities** ○ O1 Project Financed by the European Union. ○ O2 National and provincial political support; private Argentine support (Garrahan Foundation); support from local universities. ○ O3 Local characteristics (Chaco): a) absence of genetic services b) c) high level of unsatisfied basic needs c) endogamic population d) DCO in each sanitary zone interconnected and connected to our institution. ○ O4 Incorporation of human resources of the town of Resistencia with previous experience of the local team. ○ O5 Growing project: incorporation of new members in the team and offers for new destinations.	**Threats** ○ T1 Political: Change of provincial Health Ministers. ○ T2 Geographical-Sanitary: Climate (limiting the months for seminars), relief-biome (access to interior province), emergency due to dengue, floods and H1N1 influenza. ○ T3 Economical: During the development of the project (delay of the second part of the funds from the European Union); for the ongoing growth of the project (financing closed) and to maintain long-term project (European Union funding finishes December 2009). ○ T4 Sociocultural differences Buenos Aires-Chaco: lack of common culture; linguistically isolated communities, lack of access to internet/PC; low credibility of local people in national projects that make a lot of political noise but are not followed up. ○ T5 Sociocultural differences Buenos Aires-Buenos Aires: Lack of willingness of groups from other hospitals who started training programs in other areas afterwards to integrate in our project.

STRATEGIES

Strengths/Opportunities

- "Strengthen coordination and maintain the aims achieved of integration of the source group and the local group through a network" S1 S2 S3 / O3 O4 O5
- "Establish agreements of bilateral collaboration" S1 S2/O1 O2 O4 O5
- "Design a project of outreach education for on-site training in places of intensive work based on problem solving and local experience (teaching consult), design original teaching material with the possibility of participation of the local community" S1 S2 S3 S4/ O3 O4 O5
- "Implement a program to train teachers" S2 S4/ O4 O5

Strengths/Threats

- "Establish agreements with authorities above provincial health authorities and designate a local reference person for Chaco in a permanent post" S1 S2 S3/ T1 T4
- "Flexibilisation of the chronogram, contract specialised service for transfers" S2/T3
- "Fast dissemination of the preliminary results of our product in scientific societies, government settings in the coordinated regions (Chaco-Buenos Aires-European Union) and NGO Garrahan Foundation to consolidate financial and institutional support for the product" S1 S2 S3 4 / T3 T4 T5
- "Use of financial resources prioritising for the moment printed over digital material with high-quality images and contents to be applied in daily practice" S3 S4 / T4
- "Invitation for other institutions to observe on-site implementation of the processes and free supply of educational material to these groups for the use in their model" S1 S2 S3 S4/ T5

Opportunities/Weaknesses

- Implement plans for ongoing improvement (results management): redesign closed initial project to allow gradual growth and incorporation of new sectors" O2 O3 O4 O5/W1 W2 W3
- "Establish agreements that allow fund raising in Argentina independently from the European Union to allow the project to continue and grow over time" O2/W1 W5
- "Encourage cooperation in different activities in the project based on the experience of human resources in both groups"O1 O2 O4 O5/ W2 W4 W5

Weaknesses/Threats

- "Search for new funding sources among local sectors involved (Argentine NGOs) that will benefit from the project" W1/T3
- "Encourage integration in the network of source group and local group and of groups from other institutions" W2 W4 W5/T4 T5
- "In the process of modification integrate local and regional characteristics in the (political, geographic, and sanitary) planning and systematically include centralising information (updated provincial human resources data bases, surveys on resources, etc), to speed up carrying out internal processes" W3/T1 T2 T4

Activities Timetable

Activities	2007												2008												2009											
	1º SEMESTER						2º SEMESTER						1º SEMESTER						2º SEMESTER						1º SEMESTER						2º SEMESTER					
	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D
-Set up a local Capability working group -Local presentation of the project	6 months																																			
-Evaluation of background -Design of analytic framework -Presentation in Chaco -Presentation at meeting subcommittee 2 -Coordination with local authorities							6 months																													
-Report on local needs assessment																2 months																				
-Preparation of teaching materials -Design and activation of Web Page -Pilot experience Las Breñas -Presentation at Capability Meeting -Handing out of teaching materials													6 months																							
-Workshops and teaching consults in others sanitary areas																			12 months																	
-Training of teachers: -Design of capacity building -Training at the SRC -Local dissemination of knowledge																									6 months											
-Analysis of the results - Preparation of report -Demonstration of the whole project																															5 months					
-Evaluation by the Capability Evaluation Committee -International dissemination of the report																																				1m

Reference: Time for the Demonstration Project

Designing Teaching Resources:

Educational material was developed to meet the needs in the Sanitary Areas.

Syllabus CAPABILITY Argentina:

Two levels:
Taking into account the different members of the health team

Level A

- Aimed at: all members of the health care team that work in primary care, including: clinicians, general practitioners, gynaecologists, neonatologists, paediatricians. Non-medical personnel: nurses, physical therapists, clinical psychologists, health care agents, mid wives.
- Objectives:

The syllabus will be a tool to:
- Facilitate detection of risk factors in individuals, families, populations.
- Recognize affection status in individuals, families, populations.
-Register data to adequately study the patients (diagnosis, interconsult, referral, treatment, follow-up)

- Contents:

Genetic Risk Factors. Drawing up a family tree. Taking a clinical history through a systematic registration sheet. Exercises and answer key to draw a family tree. Glossary of features and dysmorphisms with photos of patients: photos of the local population will serve as examples to make recognition easier; description of physical examination.

Level B

- Aimed at: All medical professionals working in primary care
- Objectives:

The syllabus will be a tool to:
- Assist in the diagnosis. Counselling, and follow-up of frequent congenital defects in the first levels of patient care
- Identify which patients should be referred to a clinical geneticist.
- Differentiate genetic studies that may be beneficial for the patients, how to access, and when to request them.

- Contents:

Criteria of referral and interconsultation at genetic services. Identification of emergency situations in clinical genetics. Dysmorphisms: major, minor anomalies and variations of normality, clinical importance of detection. Etiopathogenic mechanisms of congenital defects. Inheritance mechanisms. Types of genetic studies: criteria of request and reach of the studies. Sample taking and shipment. Exercises and answer key.

Validation of the material:

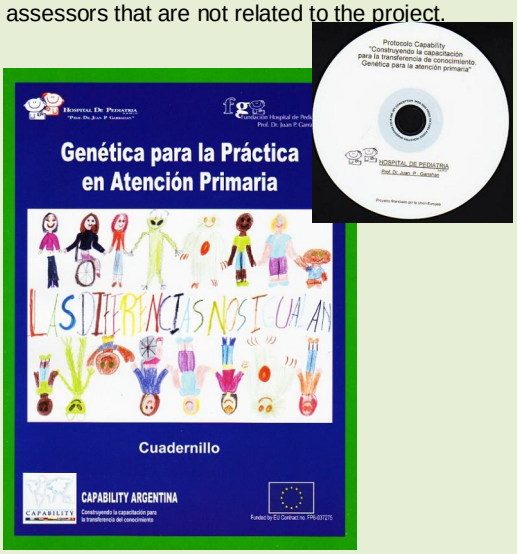
Validation of the material is performed in two subsequent stages:

1st Validation: with Users

A preliminary version was used in the participants of a pilot symposium in sanitary Zone V. During the symposium, the attendants used a printed version of the syllabus to resolve interactive activities that were given to them in the shape of clinical cases and for teaching activities that took place in the consulting rooms. The participants resolved the problems using the material, gave their opinion through a questionnaire about the design, handiness, and applicability. Result: very satisfactory

2nd Validation: Local external assessors

In progress. A printed syllabus was sent to three external assessors that are not related to the project.



Power Point Presentations

Power Point presentations are used as an audiovisual support for general courses as well as orientational classes.
All the presentations are published on the web site.

Validation of the material:

Validation of the material was carried out in the Hospital S.A.M.I.C. Garrahan. Before giving the lectures in Sanitary Zone V, they were given at the hospital. Medical residents attended the classes as pupils and staff physicians were observers and assessed the teachers.
After this first evaluation, that was considered highly satisfactory by the evaluators, only some visual aspects, such as letter type and size, needed to be improved and the presentations were taken to Chaco.

www.capabilityargentina.com.ar

Activation March 2008	Updates until December 2009

Aimed at: Health care professionals. The web page has restricted access through a password

Objectives:

- **The web page should be a means of medium- and long-term capacity building for health care professionals that work in any part of the country**
- **The web page should be a means of update of genetics in primary care**
- **The web page should allow for fast links with geneticists for interconsultation**

Contents:

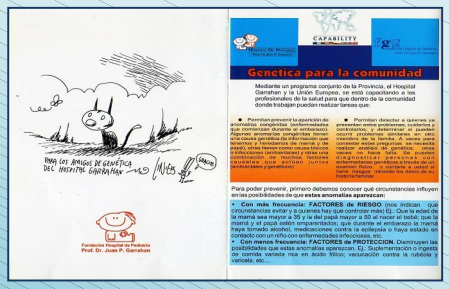
Home page: Registration (for the general public) and promotion of symposia
Second page: Options and distribution

- **Continuous education (File library of PowerPoint presentations in PDF, interviews with experts, results of teleconferences)**
- **Links with data bases**
- **Novelties (new on CAPABILITY ARGENTINA from the media)**
- **Link to forum**

Third page: Forum. Interconsultation with specialists

Folders for families:

It was decided to work with active participation of the Community, i.e. involve the community in the definition, implementation, development, and continuity of the project over time. Moreover, the training program is addressed to health care professionals as well as health care managers who are leaders in their communities.



Implementation Phase

The implementation phase is divided into three different stages:
1) Diagnosis of the Local Situation: Institutional and professional resources (Survey)
2) Initial Formation: (Distribution of digital and printed material, Workshops in Chaco for health Care professionals) // Continuous Learning: Web page activation
3) Amplification effect: Training new teachers

1) A brief summary of the process of diagnosis of the Local Situation:
A survey was conducted on health care facilities and to index human resources
Another survey was sent to health care professionals in the different Sanitary Zones, to register:

- Level of education
- Place of education and year of graduation
- If there was any kind of training in genetics at their place of education
- Current position, time in area and age range of patients
- Reasons for most frequent consults (infectious disease/multifactorial disease)
- If any of the consults was related to genetic causes
- How are cases that exceed the complexity level of the institution solved
- How would they prefer to receive the educational material (printed, CD-DVD, web page, others)

This information allowed us to have an initial view on strategies and resources that would need to be intensified.

<table>
<tr><th colspan="4">Personal Survey</th></tr>
<tr><td colspan="2">Name and surname</td><td colspan="2">Institution</td></tr>
<tr><td colspan="2">Sanitary Zone</td><td colspan="2">Department</td></tr>
<tr><td>Degree / Speciality</td><td>Position</td><td colspan="2">Time in the position</td></tr>
<tr><td colspan="2">Estimated number of patients attended annually</td><td colspan="2">Main age of group of patients you attend</td></tr>
<tr><td colspan="2">Most frequent reason of consult :
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……</td><td>Where do most patients come from?
Urban areas …..
Rural areas …..

Do you have access to a...
1. Telephone
2. Fax
3. Computer
4. Internet</td><td>Have you seen any patients with malformations?
Yes... No...
If affirmative, name which (10 most frequent)
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……
• ……</td></tr>
</table>

Have you seen any patients with genetic disease? Yes... No...	**If affirmative, name which (10 most frequent)**))))))))))
Are your patients with malformations and/or genetic disease being followed up? Yes... No...	**If affirmative, where?**
Where did you receive your professional education?	**Year of graduation** **Have you had pre-graduate training in genetics?** Yes... No...
¿ Have you had post-graduate training in genetics? If affirmative, how and where?	**Information and updates on congenital anomalies and their impact on the primary care attention as part of this course, you would prefer to receive by** Access to the web page Printed material by mail Digital Material on CD/DVD Others

- Implement this knowledge in their own daily practice (perinatology, pediatrics, adults)
- Screen for and register genetic risk factors
- Identify patients that need to be referred to a specialist in genetics
- Encourage interdisciplinary work among different members of the health care team to improve the care for individuals with genetic problems
- Help other members of the team in the diagnosis, management, counselling, and follow-up of common congenital defects
- Set up means of communication to facilitate ongoing updates (continuous education)

A diagram of the contents:

<table>
<tr><td colspan="3" rowspan="2">Group of students</td><td colspan="3">Type of content</td></tr>
<tr><td>Principles of clinical genetics</td><td>Principles of genetics in medicine</td><td>Updates</td></tr>
<tr><td rowspan="4">Health care professionals</td><td colspan="2">General</td><td>Drawing of family trees
Identification of dysmorphisms
Examples of clinical cases (teaching based on problem solving)
Principles of genetic counselling
Counselling and ethical dilemmas</td><td rowspan="4">Classification of congenital defects
Mechanisms of inheritance
Genetic risk factors
Genetic factors in common diseases
Teratogenic factors
Principles of diagnostic techniques
Burden of congenital defects</td><td rowspan="4">Training in the use of the web page for consultations/ updates/ data bases, etc.</td></tr>
<tr><td rowspan="3">Specialized</td><td>GP</td><td>In-depth knowledge of genetic factors of common diseases
Genetic and environmental factors in cancer</td></tr>
<tr><td>P/N</td><td>Most frequent syndromes
Neonatal screening for congenital defects
Ambiguous genitalia
Isolated malformations
Mental retardation</td></tr>
<tr><td>G/O</td><td>Infertility 1º and 2º
Prenatal diagnosis</td></tr>
<tr><td colspan="3" rowspan="2">Group of students</td><td colspan="3">Contents</td></tr>
<tr><td colspan="2">Teaching tools</td><td colspan="2">Principles of clinical genetics
Continuing Medical Education</td></tr>
<tr><td rowspan="4">Trainers:</td><td rowspan="2">Management</td><td colspan="2">Management, planning and coordination
Teaching: formation of new trainers</td><td colspan="2" rowspan="4">Initial training: General and with a specific orientation
Training in the use of the web page for consultations/ updates/ data bases, etc.</td></tr>
<tr><td rowspan="3"></td><td>GP
P/N
G/O</td><td>Educational strategies and technology
In the workshop
In the educational consult</td></tr>
</table>

Teaching resources:

- Overhead projector, PC.
- Class room with blackboard
- Coordination of patient appointments, availability of consulting rooms with stretcher

Activities:

The development of activities was centred on:

- Courses on basic knowledge with all participants.
- Courses with specific orientation: participation of professionals in the specific field, but open to all participants.
- The courses were divided into a first part in which knowledge was transferred and the teacher was open to questions from the participants and a second part in which cases were presented and discussed and exercises were given through a Power Point presentation that could be resolved using the syllabus.

- Educational consult: The participants were divided into different groups and under teacher guidance the patients were seen according to the practices learned in the courses: i.e. How to ask for risk factors, how to draw a family tree, how to examine the patient, how to describe the features and dysmorphisms, etc.
- Presentation of local cases: Analysis using the following strategy: Problem-based teaching: the case is resolved using the knowledge learned at the courses step by step in the educational consult using the syllabus.
- Training in the use of the web page
- Evaluation: At the end of the course, the participants were presented with a clinical case they had to resolve according to different assignments and to send to our institution for evaluation through the web page or through the distance communication office.

3) Amplification effect: Training new teachers

A training module for teachers was designed with governmental and institutional support hospital for further amplification of the model once the financing of the CAPABILITY protocol had finished.

The profile of the teachers was based on the integration of planned targets and projections with available human resources in the region.

Example:

• Health promoters: health care workers from indigenous origin people looking for missed opportunities in prevention 1st, 2nd and / or 3rd

• Paediatricians from the province's main hospitals involved in resident training programs, assessment and referral of patients by level of complexity, etc.

Teachers were divided into two categories depending on their role in the work of amplification:

• Management: planning, organization and coordination between sectors. Tutoring of other teachers.

• Effectors: Innovation, Research, Implementation strategies for the classroom workshop. Supervising learning process and strengthening of educational bodies.

It was suggested that on a training ground (unit of space where a learning situation can be implemented) these two functions would be fulfilled by different people;

However, in case of minimal availability of human resources, the management trainer can have an effector function.

List of tasks necessary for the achievement of the activities planned	Others
Search Work Field for Demonstration Project in Argentina	Chaco was chosen
Search for strategies to plan the Demonstration Project according to the context of the Province of Chaco and Genetic Needs Assessment, CAPABILITY Argentina	Strategies for teaching and the development of educational material for distance education
Logical Framework CAPABILITY Argentina	
Coordination National Authorities	
Coordination Local Authorities	There were three changes of government in the province of Chaco and changes in healthcare decision making
Data collection on the hierarchical organization and functioning of public health care in Chaco	Had to be done twice due to the changes described in the previous item
Establishment of a national working group: operative and educational	
Establishment of a local working group in Chaco in coordination with the national team	
Purchase and shipment of equipment for the coordination office in Chaco	Monitor, PC, Printer, and Internet Connection
Design of chart to index health care providers Design of chart to index human resources	
Design of educational material: Syllabus level A, Syllabus level B; PowerPoint classes, CDs. Design and activation of web page	
Indexation of health care worker conditions and human resources in Sanitary Zones: I, II,V, VI	
Purchase of equipment for education	Books and overhead projector
Analysis of indexation performed in the different Sanitary Zones	
Symposium in Sanitary Zones: : I, II,V, VI	Participation of representatives of all health care providers. A larger amount of funds was addressed to work in "El impenetrable", the most difficult and poorest zone in the area. The symposia took more time and were more expensive as a group from the ministry had to travel to train them step by step.
Data base of internal documents and Update of web page	Continuing activity
Carry out the necessary modifications of the initial Logical Framework CAPABILITY Argentina initial (continuous process improvement)	
Continuous collaboration between national working group and local working group in Chaco	
Teaching course for new teachers	Continues in 2010
Design of a Procedures Handbook	Reprogrammed activity for 2010
National e International Dissemination and Final Report CAPABILITY Argentina	Continuing activity

CAPABILITY Argentina Results:

a) Main Results of implementation phase:

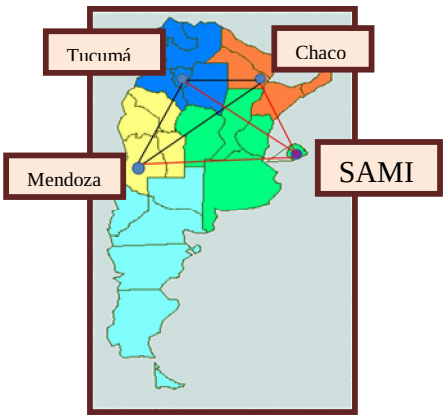
- The training took place in **4 sanitary zones: I; II; V; VI**.
- This implies that 756,648 inhabitants (**73% of the population of the province**) were covered; 3 zones did not enter the program.
- A total of **413** health care workers were trained during the demonstration Project (51 in Sanitary Zone V; 179 in Sanitary Zone I; 81 in Sanitary Zone II; and 102 in Sanitary Zone VI)

Note about SANITARY ZONE VI: CAPABILITY ARGENTINA COULD ENTER THE MOST DIFFICULT REGION, "EL IMPENETRABLE" leading to a dual result: capacity building in genetics in this extremely poor area and capacity building in management providing a training model (on-site dissemination) for future change. During the last Chaco Capability Workshop, we invited members of the Ministry of Health, authorities of the Garrahan Hospital, and teams from other institutions in an on-site demonstration of the management of the project and training of the participants

- The total number of consultations over the period 2008-2009 in the 4 sanitary zones that participated in the program was 268. This means that consultation increased significantly (**3.5 times**) in those areas comparing before and after the training period, and, notably, all had a congenital disorder. The diagnoses made in these patients did not require referral to a tertiary centre; it was only necessary to send the clinical chart, pictures, and blood samples. It resulted that the need for laboratory studies, especially in cytogenetics, increased.

From the Garrahan S.A.M.I.C. centre, a complementary project was approved with financial support from within Argentina to build a cytogenetic laboratory in the capital of the province of Chaco, for G banding analysis in peripheral blood, chorionic villus sampling, high resolution cytogenetic studies in peripheral blood, and diepoxybutane analysis in peripheral blood. Training of the technicians of this laboratory will also be sponsored by the S.A. M.I.C.

By June 2008, two projects had been started in the province of Chaco: CAPACITY BUILDING of health care workers (CAPABILITY ARGENTINA sponsored by the European Union) and NETWORK Protocol OF CYTOGENETIC LABORATORIES to build a cytogenetic laboratory in Chaco (Funding for the Project: S.A.M.I.C. Argentina)
Both projects serve as a platform for the initiation of genetic health care in Chaco; the aim is to refer to the specialized reference centre in Buenos Aires (S.A. M. I .C.) only those patients and samples that cannot be resolved locally. And additional similar laboratories are setting up in two other provinces in Argentina.



While this teaching and training was being undertaken, engagement of the community with the project and with children with congenital and genetic disorders was looked for through the media (newspapers, TV, radio, internet), open talks for the community and workshops for parents with children with congenital and genetic disorders.
During 2010 we continued training in the remaining 3 sanitary zones in Chaco and supporting of the local genetic service in Chaco (consult and laboratory). Other activities planned are: a) quality control of the genetic tests and b) progressive optimization of the laboratory network.

Number of participants in each Sanitary Area

	Sanitary Zone I	Sanitary Zone II	Sanitary Zone V	Sanitary Zone VI	Total
General Practitioners	4	8	15	10	37
Paediatricians/neonatologists	83	36	4	6	129
Obstetricians/Gynaecologists	2	2	3	3	10
Nurses	6	13	15	41	75
Educational Therapists	17	8	1	6	32
Physical therapists	6	4	2	3	15
Midwives	16	0	2	2	20
Health Care Agents	14	1	0	15	30
Others	31	9	9	16	65
total	179	81	51	102	413

Course Satisfaction Survey (Pilot project) "Las Breñas" Sanitary Zone V.

For the pilot project a questionnaire was designed consisting of 12 questions that focused on quality and were aimed at assessing the planning, organisation, and execution of this first experience with an on-site training program. Special emphasis was placed on the level of satisfaction of the participants in relation to:

The Capability team Argentina (teachers, technicians, and administrative personnel).
Contents, theoretical, practical, graphics (syllabus, CD, brochures).
Environment (environment created) in different activities as well as in social and informal relationships.
Topics as a source of professional update.
General level of satisfaction with the training course.

For each question a blank space was added for comments. At the end of the questionnaire an additional blank space was added for further personal remarks or suggestions.

The results of the survey were used as tools for concrete plans of improvement and necessary adjustments from a local perspective.

The questionnaires were handed out to all participants of the training course (n=51) and answered by 70.58 %.

In the first place the satisfaction survey was useful to know what the participants thought about the course. In the second place, we consider that measuring the level of satisfaction was a way to evaluate the work carried out by the team and the effectiveness of the communication and organisation within the Garrahan hospital and between the hospital and the local team.

Capability Argentina Course Satisfaction Survey
"Capacity building for the transfer for Genetic Knowledge into Practice and Prevention"

Please answer the following questions by checking the boxes in accordance with criteria outlined		
1 Unsatisfied	**2 Satisfied**	**3 Very Satisfied**
Note: It is very important for us to receive your feedback regarding our work and your opinion is essential for those aspects that are unsatisfied (score 1) Explain the reasons or make clarifications as you deem appropriate.		

1 What is your level of satisfaction with each area of our team?			
	1	**2**	**3**
Teaching			
Technical - Management (Organization - attention, etc.).			
Comments			

2 What is your level of satisfaction with the quality of contents?			
	1	**2**	**3**
Theoretical			
Practical			
Graphics (Booklet / CD / Brochures, etc.).			
Comments			

3 What is your level of satisfaction in relation with the environment generated in different activities?			
	1	2	3
General Seminars			
Teaching Clinics			
Orientation seminars			
Interactive Activity: "The Art of Looking"			
Social - informal			
Comments			

4 Do you consider that the topics are useful as a source of professional development?				
YES		NO		
Comments				

5 What is your overall satisfaction with the training received?	1	2	3
Comments:			

Comments /Suggestions ……
……

Capability Argentina (Pilot Project) Sanitary Zone V Results of the Course Satisfaction Survey in "Las Breñas"				
Nº of Participants: 51	Nº of questionnaires collected 36 (70.58%)			
Level of Satisfaction	Unsatisfied	Satisfied	Very Satisfied	No answer
Teachers	---	6 (16.7%)	30 (83. 3%)	---
Technical/administrative personnel	---	7 (19.4%)	29 (80.6%)	---
Quality of theorical contents	---	6 (16.7%)	30 (83.3%)	---
Quality of practical contents	---	8 (22.2%)	28 (77.8%)	---
Quality of graphical contents	---	4 (11.1%)	32 (88.9%)	---
Environment* in general seminars	---	6 (16.7%)	29 (80.6%)	1(28%)
Environment* in teaching clinics	---	5 (13.9%)	31 (86.1%)	---
Environment* in orientation seminars	---	3 (8.3%)	31 (86.1%)	2 (5.6%)
Environment* in interactive activities	---	5 (13.9%)	30 (83.3%)	1 (2.8%)
Environment* in social–informal relationships	---	5 (13.9%)	31(86.1%)	---
Do you consider that the topics are useful as a source of professional development ?			Sí	No
			36 (100%)	---

Environment*. We considered it important to measure the level of satisfaction related to the environment created in different activities as it has an important effect both on the performance of the team during the intensive work in the seminars and on the motivation of the participants to incorporate new knowledge.
The questions were designed to see what participants felt about the environment and how they established relationships. The results were supposed to reflect interactions among participants, personnel, and teachers, organisation, degree of adhesion, rejection, satisfaction, needs, expectations, etc.

Results of the Course Satisfaction Surveys in Resistencia (Sanitary Zone I), Presidencia Roque Sáenz Peña (Sanitary Zone II), and Juan José Castelli (Sanitary Zone VI)

The positive results obtained in the course satisfaction survey conducted after the Pilot Project were motivating for the team and an encouragement to continue in the work as planned.
Not all workers of the source team knew the province we had chosen to carry out the project, but all of us knew that it was one of the poorest and underdeveloped areas of Argentina.
Respect for the local and autochthonous identity and knowledge was the initial premise of our work and we searched for a shared culture of knowledge trying to make this a learning process for all.
According to Drucker of all aspects of the management of knowledge, to promote a culture of shared knowledge is probably the most important and most difficult. A key aspect of this process is the development of human networks of complementary skills and interests of knowledge workers who are willing to share their practices for the increase of productivity, new techniques, and lessons learned with colleagues worldwide. Thus, we proposed to build relationships and trust in face to face meetings as the base for the network.
For the presentation of the results, we decided to join the information collected in the three Sanitary Zones. Of all participants, 146 answered the questionnaire, accounting for 40.33% of the participants in the training courses of Resistencia (Sanitary Zone I), Sáenz Peña (Sanitary Zone II), and Castelli (Sanitary Zone VI)
In relation to the observations, comments and suggestions made in different areas were used as source of information for the construction of SWOT matrix to correct weaknesses and plan future interventions.

Presentation of Results

Participants expressed a high level of satisfaction with the course, comparable to the results of the Pilot Project.

Capability Argentina Results of the Course Satisfaction Surveys in: Resistencia (Sanitary Zone I), Presidencia Roque Sáenz Peña (Sanitary Zone II), and Juan José Castelli (Sanitary Zone VI)				
Nº of Participants: 419	**Nº of questionnaires collected 146 (40.33%)**			
Level of satisfaction	**Unsatisfied**	**Satisfied**	**Very Satisfied**	**No answer**
Teachers	---	13 (**8.9%**)	132 (**90.4 %**)	1(**0.7%**)
Workshops and seminars	---	32 (**21.9%**)	113 (**77.4%**)	1(**0.7%**)
Teaching consult	1 (**0.7%**)	62 (**42.5%**)	82 (**56.2%**)	1(**0.7%**)
Teaching materials	1 (**0.7%**)	29 (**19.9%**)	115 (**78.8%**)	1 (**0.7%**)
Friendliness of staff	---	8 (**5.5%**)	138 (**94.5%**)	---
The aims of the seminars were met		**Yes**	**No**	**No answer**
		134 (**91.8%**)	2 (**1.4 %**)	10 (**6.8%**)
Some activities should be modified		51 (**34.9%**)	92 (**63%**)	3 (**2.1%**)
The majority of participants who wanted to make modifications referred to the Teaching Consults. They had preferred to see more consultations, more patients, a longer time to practice, and to repeat the activity with the possibility of working in smaller groups reducing invasiveness for the patients and their families.				

1) Information on the Office of Distance Communication

- The OCD of the Garrahan hospital, inaugurated in August 1997, is a novel system of consultation open to all public hospitals of the country. More than 850 consultations are made daily.

This way of inter-hospital communications allows:

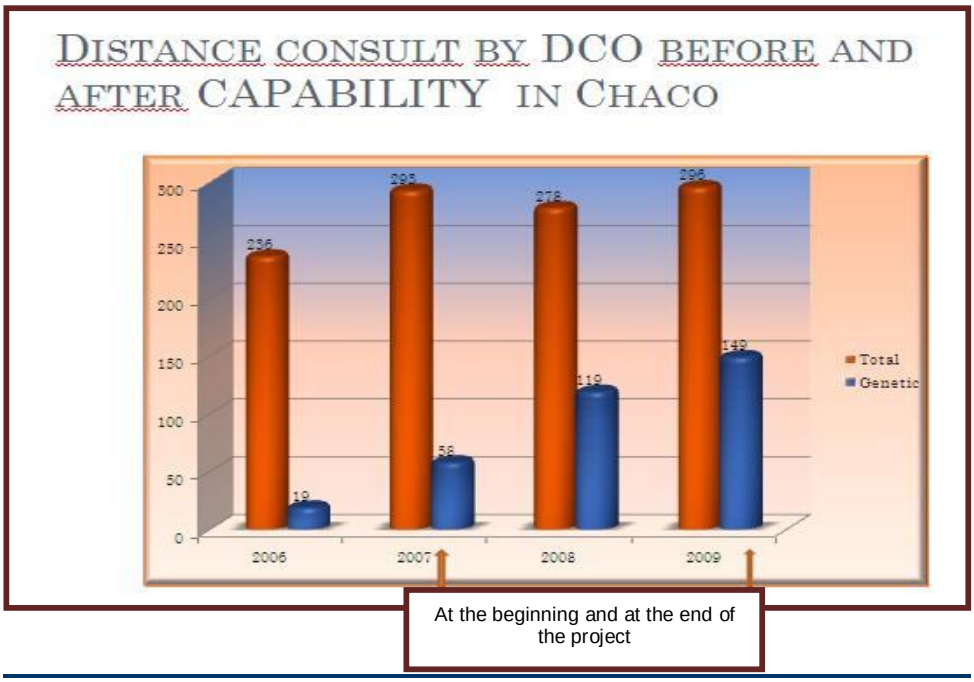
- Joint follow-up of the patient in his/her place of origin by both the local team and professionals from the Garrahan Hospital.
- To facilitate and complement the exchange of information on the diagnosis, evolution, and follow-up of patients from the provinces admitted to the Garrahan Hospital.
- Scheduling of patients for diagnosis or treatment in Day Hospital if referral of the patient is decided after consultation.
- Receipt and shipment of samples and studies (images / genetic or immunology studies / revision of blocks for pathology, etc.)
- Information on guidelines for diagnosis and treatment.
- Response to consultations on medicines (drug interactions, side effects, dosage, contraindications, etc.)
- Literature searches.
- To contribute to the National Network of Educational Psychology and Speech Therapy based in the Garrahan Hospital by sending brochures to the hospitals that start participating in the network.

This communication system for public hospitals is **free** and aims at channeling different consultations in an attempt to solve them without transporting the patient. The experience shows that in the majority of cases diagnosis can be made or treatment can be given in the place of origin of the patients.

Currently, 80 hospitals throughout the country are connected with the DCO and 20,000 consultations have been made.

Given the good results, it was proposed to introduce the system locally in the provinces. To date, DCOs have been set up in the provinces of Jujuy, **Chaco**, Catamarca, Misiones, Santiago del Estero, Tucumán, Tierra del Fuego, and Neuquén and this process of health care is progressively being developed in the remaining areas of the country. The aim is to establish a network in each province that interconnects local centers and at the same time connects with the Garrahan Hospital.

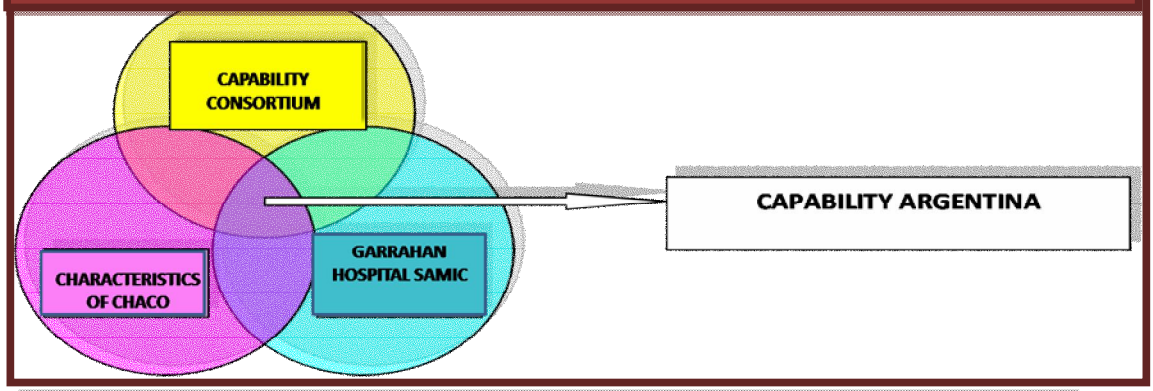
The **Office of Distance Communication** works with ***Videoconference*** equipment to transmit real-time images and data. In our country, the advent of this technology has made it possible to share academic, teaching, and consulting programs among institutions that use the same system.



Sustaining the project in time

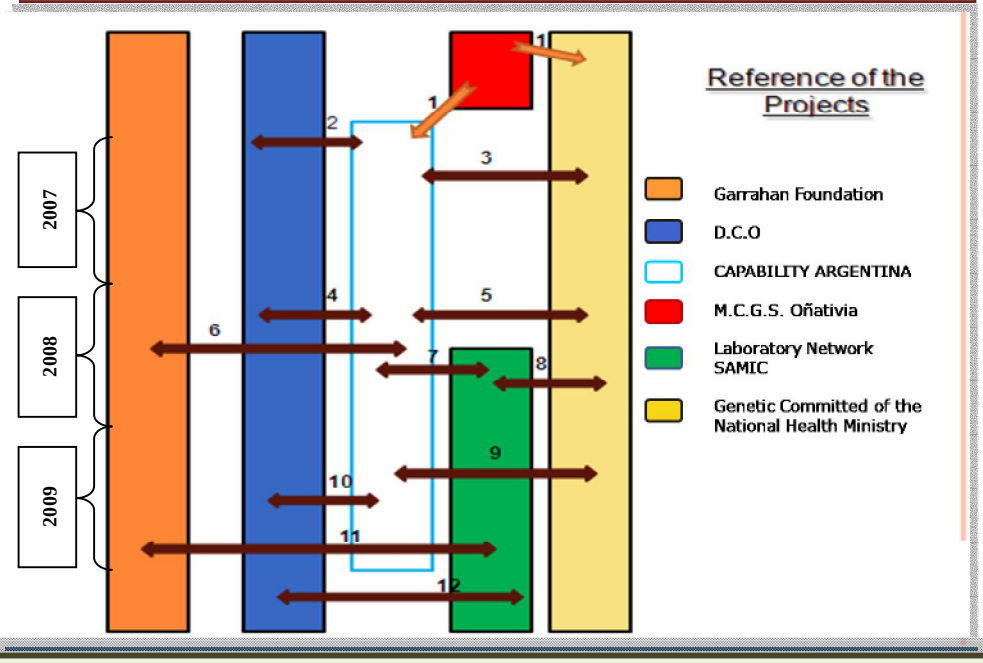
To sustain the benefits of the project in time, internal and external interactions took place that enriched the project during its implementation stage as well.

Diagram of Internal Interactions



By the CAPABILITY Consortium the basis was laid for the systematization and administration of the project. During the workshops of the CAPABILITY Consortium it became possible to bilaterally share the results and implement new ideas in the Demonstration Projects of the different partners.
As such, we began to involve the community in the aims and activities using ideas from: the Oxford Meeting: the GIG partner shared brochures and other materials for the community; the South Africa Meeting: the partner from Egypt shared material for the training of community leaders, the partner from South Africa taught us how to set up laboratories with faster technology at a lower cost for the screening of chromosomal anomalies in communities with a large and poor population.
Bilateral interactions with the health care professionals in the province of Chaco allowed us to adapt the logical framework to the characteristics of the area.
The Garrahan Hospital gave us the institutional framework and the expert health care team for the design and implementation of the model.
These interactions made it possible to sustain the project and meet the objectives planned for 2007-2009.

Diagram of External Interactions and its results



The diagram shows that the CAPABILITY project in Argentina was not closed, but open to interaction with complementary projects. These interactions assured continuity of the project when the European financial support had finished.
Details of the interactions that assured continuity of the project in time and space are the following:

1) MCGS Oñativia: the MULTICENTER COLLABORATIVE GENETIC STUDY Carrillo-Oñativia was a multicentre project for the assessment of the capacity of genetic services in different areas of Argentina (between 2006 and 2007) supervised by Dr. Barreiro that served as a basis for the start of the current program for the construction of the Network for Genetics of the National Ministry of Health and for the design of the Logical Framework Capability Argentina.
2) The installation of a DCO in Chaco in 2006 allowed the different sanitary zones and the source institution to be interconnected for the planning and carrying out of the project from the start; currently it assures the continuity of interaction among the zones where the training has taken place.
3) Joint construction of the Needs Assessment ARGENTINA
4) As a consequence of the results of the Capability project Argentina (increase of consultations through the DCO) priority was given to Chaco to improve the communication team.
5) Presentation of the Logical Framework Capability Argentina and the preliminary results of Las Breñas (Sanitary Zone V). The Committee of the Ministry of Health decides to implement a program based on Chaco in the other provinces in northeast Argentina.
6) The Garrahan Foundation is asked to sponsor the necessary improvement of the quality and quantity of the Syllabus. Thus, it becomes possible to hand out a syllabus per person in Chaco and in other provinces.
7) The training in Chaco exponentially increases the number of consultations and samples to be analysed in the laboratory, beyond the capacity of the laboratory. The hospital direction and Dr. Barreiro develop a project for the installation of laboratories in three different locations in the country, being Resistencia (Sanitary Zone I Chaco) one of them.
8) The project Network of Cytogenetic Laboratories also collaborates with the program for the Genetic Network of the Ministry of Health.
9) Integration in the Network of the Ministry of Health; CAPABILITY Argentina and the Network of Cytogenetic Laboratories.
10) Idem 4 in 2009
11) The Garrahan Foundation proposes to continue sponsoring the training model in 2010 in the remaining Sanitary Zones in Chaco and in other provinces as well as the training of personnel for the new laboratories of the Network of Cytogenetic Laboratories.
12) Optimization of the shipments of samples for analyses not performed in the new laboratories; supervision of practices in the new laboratories.

CAPABILITY Team Argentina

During the implementation of these first stages of the project, a working group was set up.
The team was subdivided into a source or national team and a local team.
There have been specific areas for each team as well as joint capacity building areas.
In the setting up of the working group, the underlying idea was the existence of a problem in common and the possibility of systematically working together in the organisation of activities. The initial asymmetry in training/information of the members of the team was compensated by the creation of a common vision through the joint construction and empowerment of the model by which the members became agents of change.
Steps in the organisation and strengthening of the teams and their interrelations:

Level of commitment	Actions
5 Association	**Share goals and plan new projects**
4 Cooperation	**Share activities and/or resources**
3 Collaboration	**Lend sporadic, situational help**
2 Knowledge	**Knowledge of what the other is doing**
1 Recognition	**Incorporate the other as an interlocutor**

Correlation of the level of commitment and the years of the CAPABILITY project

In 2007 the basis was created for the local and source teams to communicate at level 1 and 2. In 2008, level 5 was reached and in 2009 the teams centred on level 5.

Members of the team:

Cristina Barreiro MD
Director CAPABILITY ARGENTINA.
Participant 7 SAMIC of the International CAPABILITY project

Maria Paz Bidondo MD
Fellow CAPABILITY Argentina project

1. Source Team:

- Directors of SAMIC**: Josefa Rodríguez Rodriguez MD and Patricia Elmeaudy MD**

- Teachers: **Cristina Barreiro MD, María Paz Bidondo MD, Fernanda de Castro Perez MD, Jennifer Garrido MD, María Luz Teiber, María del Valle Torrado.**

- Management and technical support: **Eduardo Acevedo accountant (Advisor in management and financial support), Juan Corvoisier MA (Web Master), Janneke Deurloo MA (Translator), Antonio Luna MA (management technician)**

2. Local Team Chaco Province:

- Local coordinator CAPABILITY Argentina: **Emilce Gutierrez MD**
- Local medical team: **Emilce Gutierrez MD, Carolina Dellamea MD, Claudina Picón MD**
- Local management and technical support: **Edith Karin Torres, technician.**
- Local transport: **Mr Dante Vallejos**
- Collaborators in each Sanitary Region:

Sanitary Zone I:
Zona I: Alarcon Lorena, Cantero Estela, Liliana Villalba
Zona II: Dr. Marcelo Torres Perez, Alario Gladis Alicia, Veronica Selena Barrios
Zona V: Dr. Sandra Mabel Palacios and Mr. Daniel L. Osentiuk.
Zona VI: Dr. Cecilia Maza – Ms. Patricia Ledesma.
In charge of transport in the area: Mr. Dante Ernesto Vallejos

In conclusion: The CAPABILITY Argentina cycle

Beneficiaries: Direct: Attendance at training sessions

Indirect: Benefit of the training project was not only for the inhabitants of this area with a severe lack of socioeconomic resources, but also, through the support of the Ministry of Health, for the inhabitants of the whole region**.**

Unplanned effects: Although the aim of the project was the training, it set in motion the systematic care, genetic counseling, and specialized studies for patients with purely or partially genetic conditions.

Another unplanned effect was the start of a project for the setting up of a laboratory in the region.

***Evaluation of the impact*:** On the one hand an increase in the number of distance consultations was observed and on the other hand improved results were seen in the satisfaction surveys as well as in the number of participants in each Sanitary

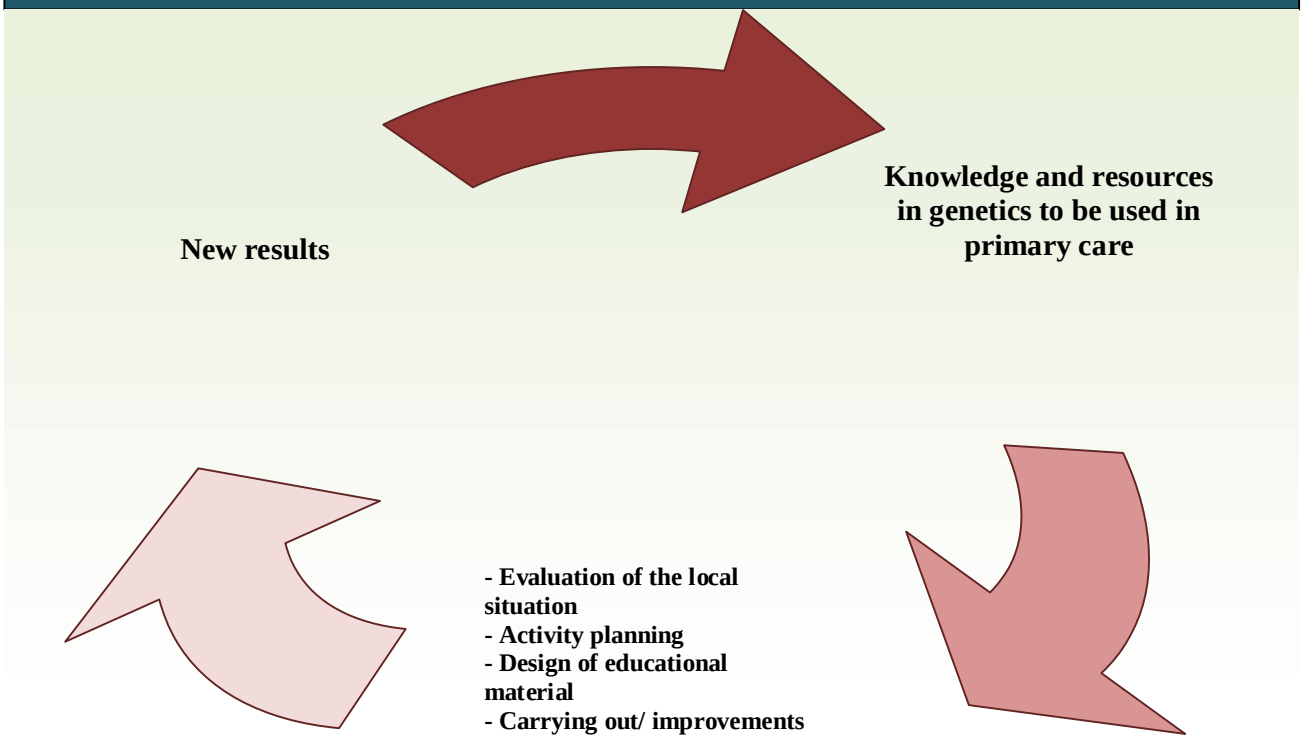
The process of planning and carrying out the project and the transference of technology and knowledge (for primary care in genetics in the province of Chaco) worked as a **CYCLE**.

To sustain the cycle, positive feedback from new results and continuity in time are necessary. Gradually to the local cycle in CHACO the proposition of replication-amplification of the model was added. Replication in this case meant the carrying out of the model in other provinces and amplification meant feedback of the model in Chaco both in the training areas and in the remaining zones establishing a matrix of several coordinated and interconnected cycles.

The results of the project suggest that replication and amplification should be carried out by local human resources as the development of the model requires many hours of dedication by highly educated and expert personnel as well as and funding for travel and accomodation of personnel due to the distance between the source institution and the local area. This last point together with the results mentioned below prioritize the following needs:

a) To work in a network with multiple and interconnected centres with different hierarchies.
b) To work together with complementary projects.
c) To design a procedures manual to use as a general guide for the replication of the model in other areas in the country.

CAPABILITY ARGENTINA CYCLE:



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