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EDUCATION, IDENTITY AND PEOPLE WITH APHASIA

TOWARD AN ECOLOGICAL APPROACH

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PREFACE

..the aphasia disappears...
the person with aphasia remains...

(from Living with Aphasia: Psychosocial Issues by: D. Lafond Y. Joanette J. Ponzio R. Degiovani M. Taylor Sarno, Editor)

I am the chairwoman of ALIAS, an Association made of persons with aphasia, relatives and professionals. We share the vision of aphasia developed by the Aphasia Institute in Toronto and by Connect in London, we believe in the model they have designed and we are inspired by them in organizing our group and individual activities.

Although ALIAS is a small reality in its country, we try to spread the social model of disability and we encounter great difficulties at all levels. In Italy the medical model is still very powerful and the quality of the education and training of speech therapists is quite low. In the speech therapist's daily practice there is a total lack of attention to important topics like the involvement of persons with aphasia and relatives in every step of the rehabilitation process, the accessibility of information to persons with aphasia and, in general, all the problems related to therapy for developing identities.

We have good contacts with Canada and USA, to confront ourselves with centres and researchers interesting for our own activities.

Two years ago, having chosen a model not well known in Italy and feeling isolated, we decided to participate to a European

Learning Partnership that involves – beyond Italy - Sweden, Ireland, Estonia, The Netherlands and Finland. Scope of the Learning Partnership is to share and exchange knowledge in how to provide and improve education/training for adults with acquired aphasia.

This report is one of our contributions to the Project.

INTRODUCTION
ON CONTROVERSIAL ISSUES

Enabling People for a democratic pedagogy

The main topic. This paper is a short essay on "Learning and Aphasia", an investigation on what can be done to promote learning for people with aphasia and facilitate their inclusion in educational experiences. The research was lead within LAPH[1], a Learning Partnership financed by the Grundtvig 2 EU Action of the Socrates programme.

Learning is a psychological process that can take place in any context. This report focuses on learning processes finalized at several aims (professional development, self-realization, active citizenship), considering different educational activities (formal and informal, intentional and incidental) and placing them in the context of concurrent theories on adult learning.
Obviously it doesn't answer every question about learning and aphasia, or solve the complex relationship between lifelong

[1]For information about LAPH, view the Project's website: www.aphasiaforum.com/sitolaph/aphasia.htm

learning[2] and lifelong illness that is multi-faceted[3]. However, by lightening some of the ways through which education can add "quality" to the life of people with aphasia, the study provides a better understanding of the problems.
In fact learning can and does empower, but it can also be a mechanism for exclusion and control creating or maintaining power inequalities.

For these reasons, this report explores issues like power, politics and society, drawing on many references; not only on the International Classification of Functioning, Disability and Health (ICF) as a framework for understanding the complex phenomena that come together to form education for students with aphasia[4] but especially on andragogy principles. These, in

[2] Lifelong learning enables individuals to achieve their potential, including those excluded from more formal learning opportunities, either in the past or currently. In addition to formal qualifications, lifelong learning brings wider benefits, including a sense of belonging and identity and personal growth and development.
[3] Learning to live: the relationship between Lifelong learning and lifelong illness, Sue Jackson, Int. J. Of lifelong education, vol. 25, no. 1 (january-february 2006), 51–73
[4] The ICF provides an integrative approach that acknowledges the need to consider the level of functioning and disability, and contextual factors when examining the consequences of chronic conditions. The functioning and disability aspects may be of particular importance for someone who is learning to adjust to the changes resulting from an acquired disability, such as aphasia and is

fact, are in particular pertinent in an empowering context since "andragogical practice is a collaborative venture which involves the learner in most of all instructional functions"[5].

Aphasia as social construct. Moreover this report represents an opportunity to discuss about aphasia as social construct. A deconstructive criticism on aphasiology suggests that aphasia, like other disabilities, is constructed artificially so that it cannot be localized or explained only by brain mechanism[6]. It is not an organ, a cancer, a foreign body, which can be removed and examined, a disease which has to be cured or a subject to be patronized creating psychological dependency, as often happens. It is an issue concerning human rights: all aphasic people experience their disability as a social restriction, whether these restrictions occur as a consequence of "unsupportive" environments, questionable notions of intelligence and social competence, the inability of the general public to use "communication ramps[7]", the lack of accessible

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perhaps keen to find a job and/or seek further education as a means of 'returning to a normal life'

[5] Andragogy as a relational construct. Adult Education Quarterly, 38 (3), 160-181. Pratt, D.D. (1984).

[6] Aphasia: some neurological, anthropological and postmodern implications of disturbed speech. Thesis by Rochelle Smith Doody, 1992

[7] i.e. to provide access to social conversation

material or hostile public attitudes to people with non-visible cognitive disabilities. Moreover, people with aphasia are not a homogeneous group: their disabilities are influenced by class, race, gender, sexuality and age factors. These can cushion or compound the experience of discrimination and oppression.

Therefore, the distinction between "having" aphasia" and "being" a person with aphasia is the fundamental general inspiration for this work. It has no meaning to promote individuals through demagogic and false solutions without connection with the actual person's empowerment.

So it is not possible to consider education without considering issues like identity and the roles assigned by the social context to people with aphasia.

For these reasons, I will not consider aphasia a "disease", neither considering the clinical forms nor the relationship between cognitive functions, learning abilities or technological devices aimed at improving learning. I would like to focus on the competences of the person with aphasia as a learner, and on the implementation of these in the different educational contexts. Of course we cannot forget the importance of the

teacher[8], who is the co-star in the educational pathway. A reflection on pedagogy and the need of rethinking it in the context of the current sociological debate is also very important. A striking example is the recent review of the concept of "learning motivation" which, according to Helene Ahl[9] should be considered as a relational concept, rather than as residing within the individual, or the gender perspective[10].

Gender. Gender is very often ignored; the person is considered regardless his/her sex which is, of course unacceptable. The topics of race and gender are not widely discussed within the field of adult education yet as they should be, since the attention to gender is of utmost importance to understand the importance of overcoming stereotypes on disability; in particular the intersection of gender, race and class and their role in shaping ideas and perceptions on learning process. It is necessary to be transparent in recognizing gender as a fundamental topic. It means also to

8 given the link between therapy and learning , when I speak about teacher I mean also trainer or Rehabilitation staff, all those who must pay attention to learning processes

9 Helene Ahl. Motivation in adult education: a problem solver or a euphemism for direction and control? Int. J. Of Lifelong Education, vol. 25, no. 4 (july-august 2006), 385–405

10 "Gender" refers to the social roles, responsibilities, and behaviours that are believed to belong to men and women

avoid organizing learning support organized from a merely functional point of view, focusing on the performance of a "neutral" subject[11]. We can, instead assume that women and girls with aphasia find it more difficult to advocate themselves in the educational arena than either their disabled male or non disabled female counterparts. It is a double discrimination that we also find in rehabilitation, since in some parts of the world there are gender differences in the utilization of a community rehabilitation program[12]. It is therefore necessary to develop a democratic pedagogy based upon gender equality and the recognition of differences. Promoting gender equality and creating a more gender inclusive teaching program (through gender-sensitive curricula, learning materials, and teaching-learning processes) is an important part of all areas of education. And it also means that we need to move away from looking at women and men collectively as "students" and to focus more on the specific situation of "women" and "men"

11 Madeleine Arnot. Gender equality and opportunities in the classroom: thinking about citizenship, pedagogy and the rights of children. Paper presented at the Beyond Access: Pedagogic Strategies for Gender Equality and Quality Basic Education in Schools, Nairobi, 2 - 3rd February, 2004.

12 Tamiya N. et al. Gender Difference in the Utilization and Users' Characteristics of Community Rehabilitation Programs for Cerebrovascular Disease Patients in Japan. International Journal for Quality in Health Care, Volume 8, Number 4, August 1996, pp. 359-366(8)

within the classroom and school to ensure gender equality in learning for both.

Rehabilitation. Since educational and rehabilitation issues are very close, in our report we will often refer to rehabilitation. And particular critics will be focused on the significant influence of forms of “rehabilitation” thinking on practice, in relation to the identification and implementation of disabled adult’s competences. I mean the typical reductionism and the emphasis given to deficit and dependency-creating assumptions. To avoid these type of attitude, since I am myself a rehabilitation professional, I will try to understand (in a experiential dimension) how people, who have difficulties with the fundamental medium for learning, language, can access this aspect of life so deeply tied to adulthood. To succeed it will be necessary to consider the learners point of view, regarding the role that they and we should play in an educative experience. Based on concrete experiences, we will, for example, verify that people with aphasia have a lot of problems in participating to academic courses, without learning support. As stated by Carolyn Bruce :

"Aphasia, in fact, is of particular importance in an educational context, as effective language skills are needed for

students to understand spoken and written information, take lecture notes, complete coursework and sit conventional examinations. Communication skills are also important for joining in the social aspects of education. In addition to aphasia, people who have had a stroke may have residual cognitive, emotional, social and/or physical difficulties. Members of staff who are unfamiliar with stroke and aphasia might not anticipate the person's communication difficulties and the subsequent problems he or she might have in carrying out academic and social activities. To make matters harder some people who have had a stroke will have no visible characteristics of disability; thus it might not be immediately apparent that there are any problems. In other cases, the person might have a physical disability such as a hemiplegia. Here, there is a risk that staffs' responsiveness to the individual is limited to his or her problems with mobility. A greater awareness and understanding of aphasia would increase the likelihood that staff would be receptive to the needs of an individual who has had a stroke. However, the support process would be even more effective if it was based also on what people with aphasia reported facilitated their learning". Carolyn Bruce et al. "[13]

[13] Helping or something': perceptions of students with aphasia and

Obviously there are no quick or easy answers, but it is very useful to explore the issue and draw a *conceptual map* of which this report[14] represents an outline.

Theoretical Framework. A theoretical framework is a collection of interrelated concepts, like a theory but not necessarily so well worked-out, which structures a systematic view of phenomena for the purpose of explaining or predicting. It is very important because it is impossible for a human being not to have preconceived notions, in particular for rehabilitation professionals. They often have strong prejudices against the learning potential of people with aphasia, usually considering their goals as unrealistic compared to their real competences. Considering abilities and skills as standard elements, without keeping in mind the deep differences among individuals, affects the way they lead their patients in the inclusive phase. We must also reflect on the regulating ideal underlying any education/rehabilitation activity which considers the subject respect "static variables" (like skills and competence), in contrast with the right for

tutors in further education. Carolyn Bruce, Ann Parker and Laura Renfrew, International Journal of Language & Communication Disorders, 2006, Vol. 41, n° 2, 137–154

[14] presented to the LAPH Meeting held in Dublin in April 2007

everyone to be considered as a unique individual and the right, also for the ones who risk to be "deracinè"[15] because their language difficulties, to be active part of the society. Actually, we are always guided by a theoretical framework, even if we are not aware of it. This lack of awareness can become a problem when someone does not even notice things that do not fit her/his framework.

Finally, this paper aims also at stimulating rehabilitation professionals to reframe current thinking about aphasia management in terms of renegotiation or reframing of identity.

"People with aphasia and their significant others are at risk for identity theft"[16]

[15] Uprooted, eradicated

[16] Aphasia as identity theft: Theory and practice. Barbara Shadden, Aphasiology, Volume 19, Numbers 3-5, Number 3-5/March/April/May 2005

CHAPTER 1
THE HIDDEN DISABILITY

Linguistic disadvantage

" Language makes people equal. Equal is someone who can express himself and understand others. It does not matter if he is rich or poor as far as he can speak"

Don Milani, Lettera a una Professoressa, 1967[17]

Aphasia is a blank term covering a broad spectrum of language difficulties brought about by cerebral lesions[18]. People with aphasia are a large, diverse group, although it is difficult to determine exactly how many are included, also because there are many definitions of aphasia[19], not only across countries but also within the same country. Aphasiologists are currently making an effort to achieve a new international definition that considers many factors (in what

[17] Lettera a una Professoressa, Scuola di Barbiana, Firenze, L.E.F. 1967

[18] Most often cerebral vascular accident which is more commonly known as stroke

[19] Defining aphasia: Some theoretical and clinical implications of operating from a formal definition. Malcolm R. McNeil and Sheila R. Pratt, Aphasiology, 2001, *15* (10/11), 901–911.

case can we speak about aphasia? Can we speak of aphasia only when all the levels of the language are compromised? Also in dementia or brain injuries?), but no consensus has been reached yet.

With regard to epidemiology, given the diversity of definitions, there are no clear statistics on the number or percentage of people with aphasia. One international research on the incidence of stroke in the world[20] shows that in Europe, Russia, Australia, and United States, there are similarities in incidence and pathological types. This is not a surprise since all the surveyed individuals were westernized and mainly white[21]. In brief it has been estimated that annually 15 million people worldwide suffer from a stroke and even assuming that about a third of the people who experience strokes are affected by aphasia, as some researches[22] suggest, the number of people with aphasia worldwide is likely to be substantial high. But epidemiological data or structured definitions don't tell us

[20] Sudlow CL, Warlow CP. Comparable Studies of the Incidence of Stroke and its Pathological Types Results From an International Collaboration, *Stroke.* 1997;28:491-499

[21] This homogeneous distribution of the disease in the industrialized world suggests that the environmental factors (life style, food, smoke, lack of exercise) play an important role as risk factors for ictus incidence.

[22] Pedersen P, Vinter K, Olsen TS: Aphasia after Stroke: Type, Severity and Prognosis. *Cerebrovasc Dis 2004;17:35-4*

anything about the life conditions of the individuals with aphasia.

A social perspective

As mentioned before, disability - to a large extent - is a social construct and has different meanings depending on the different historical periods and cultural contexts. Every definition of disability specifies something about the underlying theoretical assumptions.

“Most people believe they know what is and is not a disability. If you imagine "the disabled" at one end of a spectrum and people who are extremely physically and mentally capable at the other, the distinction appears to be clear. However, there is a tremendous amount of middle ground in this construct, and it's in the middle that the scheme falls apart. What distinguishes a socially "invisible" impairment - such as the need for corrective eyeglasses - from a less acceptable one - such as the need for a corrective hearing aid, or the need for a walker? Functionally, there may be little difference. Socially, some impairment creates great disadvantage or social stigma

for the individual, while others do not. Some are considered disabilities and some are not."[23]

So it's very difficult to define disability without the consideration of social factors. The medical model, an outmoded intellectual framework that continues privileging physiological/biological aspects, defines disability as a de-personalized medical problem, requiring diagnosis and treatment. In this way the person is defined by his/her disability, without considering sociological and psychological aspects.

Aphasia, is often seen in terms of medical ideology like an acquired disorder caused by brain injury that affects the person's ability to communicate. It is considered one of the most disabling symptoms after stroke and a strong barrier against independent living. From this point of view, as Robert Mackay[24] says, aphasia is built on the medical ideology that propose a personal tragedy theory, i.e. a problem based on the individual and dominated by the profession of psycholinguistics who have the expertise to regulate what

[23] Deborah Kaplan, Director of the World Institute on Disability. http://www.accessiblesociety.org

[24] 'Tell them who I was': the social construction of aphasia. Mackay R. Disability & Society, Volume 18, Number 6, October 2003

adjustment has to be made. According to the medical model, people with aphasia are defective. And like Charles Goodwin says in an interview[25], there can be tremendous stigma attached to aphasia, and indeed many spend their lives in relative isolation after a stroke.

"People with aphasia are incompetent—having no voice under the communicative practice of a medical ideology. The medical ideology is hegemonic: the dictionary meaning for aphasia, defined as the loss of power of expressing ideas in words, seems to go against the idea of communication which is defined as to impart information, to reveal, to convey (...) This medical ideology of ableism can only construct people with aphasia in a place of containment, as voiceless and with a body marred by weakness or paralysis, which makes them dependent"[26].

In this report, like in my epistemological approach, I choose an alternative model[27] that depicts the person with aphasia[28] in

[25] http://appliedca.co.uk/
[26] ibidem
[27] The social model of disability, i.e. the product of the struggle of disabled people and their organisation against discrimination, exclusion and oppression and their desire for a better life based on

an anthropological context, particularly noticeable to professionals of educational field and useful to obtain a holistic view of the effects of communication disability on the persons' learning potentiality. Aphasia is a social issue, evaluated from an interactive and social perspective[29], rather than a purely medical one. People with aphasia are not "ill" clients or patients of somebody[30]; they are rather groups at high risk of social exclusion since positioned in an elitist "knowledge society" and in an "in-competence producer" medical culture. In a context which does not support integration, because of its competitive aspects, and in which

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alternative definitions and understandings relating the issue of disability

[28] We will not deal the problems of people with progressive aphasia, disorder caused by degenerative diseases of the brain, in which speech and language functions deteriorate gradually over a period of years, while memory and other abilities remain relatively preserved

[29] The Social Model of Disability proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical or psychological differences from a statistical norm, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal'

[30] It's wrong to mix up the neurological pathology (stroke, trauma and tumor) which requires the medical therapy with the communication problems which require the help of a team of professionals according to their professional skills. Persons with aphasia are patients when they need to have specific therapies (hypertension, depression, epilepsy…).

health institutions offer the opportunity to create inequalities but also the instruments to do it[31], impairment very soon becomes handicap and life long learning, fundamental for those who have lost the possibility to carry out their previous social role, becomes an illusion. The environmental and social barriers that exclude people from mainstream society are imposed on top of any impairment experienced, it is not the absence of "ability" per se that creates the barrier to participation.

So, disability related to aphasia is the result of inadequate collaborative efforts rather than a direct consequence of the language disease. In fact the heart of the problem is the passive attitude of the community towards service and self-help philosophy which have been instead theorized and successfully applied in some "enlightened" societies (US, Canada and UK). I refer to the core values of the Life Participation Approach to Aphasia[32] and the set of "communication ramps" developed by Aura Kagan and

[31] Constructing (in)competence: Disabling Evaluations in Clinical and Social interaction. Dana Kovarsky, Judith F. Duchan, and Madeline Maxwell, Lawrence Erlbaum Associates Publishers, 1999

[32] Chapey, R., Duchan, J.F., Elman, R.J., Garcia, L.J., Kagan, A., Lyon, J.G., & Simmons-Mackie, N. (2001). Life participation approach to aphasia: A statement of values for the future. In R. Chapey (ed.), Language intervention strategies in aphasia and related neurogenic communication disorders.

applied at the Aphasia Institute of Toronto and Connect[33] in London.

"Unfortunately, most societies value independence, measure identity in terms of contributions, and reject illness and impairment. By definition, the individual with aphasia no longer fits in that social milieu, at least not immediately post stroke. Instead, virtually all the roles and contracts that define one's sense of identity within the larger society are modified by stroke and consequent aphasia.

Persons with aphasia and their significant others face a profound social dysfunction in life. Their greatest loss may be the reduction in the fluidity and flexibility with which communication allows navigation of the complex challenges of life's social actions and interactions. Their greatest challenge is to renegotiate identity. That renegotiation must occur despite a chronic impairment of the very language that is needed to scaffold both performance of social activities (work or play) and human affiliations within the family, social groups, institutions, and the very culture itself. At stake is the

[33] Connect is a national charity creating new opportunities and a better quality of life for people with aphasia (communication disability (http://www.ukconnect.org)

desire to reestablish homeostasis or equilibrium in old and new environments"[34]

It is a "social" problem which focuses on the delicate negotiation between the individual and his/her social context aimed at the creation of new social roles, rather than on the medical aspects.

As stated by Charles Goodwin, in America and in Western Europe, there is a tremendous focus on the individual as the locus of all cognitive life, while it would be important to focus, instead, on how actions and utterances do not emerge from the psychology of an isolated individual, but through the way in which human beings build meaning and action in concert with each other through the use of systematic interactive practices. Focusing on the real competencies of people with aphasia, and the way in which such competencies require interaction with others, might begin to ameliorate stigma and isolation.

[34] Renegotiation of Identity: The Social Context of Aphasia Support Groups. Barbara B. Shadden and Joseph P. Agan. Topics in Language Disorders, July/September 2004, Volume 24 Number 3, Pages 174 - 186

I think this perspective is especially important in education, because if aphasia is a social construct is may be also a subject of social action[35].

The management of this problem requires collective responsibility in order to make the environmental modification necessary for the full participation of adults with aphasia in all areas of life, including education. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. Disability thus becomes a political issue.

The inclusive philosophy

Available information demonstrates the lack of policies and programs specifically addressed to the educational needs of aphasic people, and the failure of disability equity programs to serve them. Research is limited and consists largely of specific experiences.

[35] Social action refers to any action that takes into account actions and reactions of other individuals (real or imagined) and is based on those events or is the action including inaction that is oriented to the behaviour of others.

People with aphasia can very rarely access to "formal" education"[36], while very often they carry out "informal" education or contextual rehabilitation activities. These data are part of a larger picture of discrimination based on disability that pervades the lives of people with aphasia in all areas. Negative attitudes about people with aphasia compounded by negative attitudes towards cognitive disability are underlying this discrimination. These often cut across cultures in the most of western countries (the "malignant social psychology" discussed by Kitwood referring in particular to people with dementia[37]).

People with aphasia, as "disabled", are commonly stereotyped as sick, helpless, childlike, dependent, incompetent and incapable to learn, which of course limits their options and opportunities. And also, the biggest barrier to educational equity may be their invisibility. Even among the initiatives aimed at protecting the rights of disabled, very often there is

[36] Learning, typically provided by an education or training institution, structured (in terms of learning objectives, learning time or learning support) and leading to certification. Formal learning is intentional from the learner's perspective.

[37] Kitwood T, Dementia Reconsidered: the person comes first. Open University Press, Buckingham, 1997

no hint to the problems of people with aphasia, as if the lack of "normal" language abilities made their problems unsolvable from the possible intervention perspective. A big role is played by the heterogeneity of aphasic people and the fact that the access to education is affected not only by their different type and severity of disability but also by the socioeconomic status.

So, except rare experiences, people with aphasia continue to be excluded from the educational system for many reasons: the common idea about their *deficient cognitive functioning,* certain rigidity in teachers' attitudes and the uncertainties of some therapists that inclusion will benefit their clients. Instead, rehabilitative agencies often offer traditional impairment-based language therapy and nothing else.

In particular in my Country[38], despite a growth of interest in widening access and participation and in inclusive higher education, the voices of aphasic people themselves have hardly been heard. Therefore there are at best a handful of programs[39] specifically designed for people with aphasia,

[38] Italian law has supported inclusive education since the 1970s (nowadays more than 99.9% of all disabled children are educated in ordinary schools).

[39] Programs organized by ALIAS, Italian Not for Profit Organization formed by people with Aphasia [www.afasia.it]

while there is a range of policies and programs to promote educational equity for people with other disabilities and develop inclusive education in mainstreaming. Similarly, while strong disability rights legislation has produced a range of efforts to promote educational equity for disabled children, few have been adult-oriented or have included specific components to address the unique barriers facing aphasic people. For example, people with aphasia require the support of different professionals working all together to improve the quality of their life, yet the concept of partnership between professionals of the field is in Italy completely ignored. The general assumption is that the rehabilitating process will require the active assistance of professionals, family members and caregivers. So, in Italy, there is still a *huge gap* between inclusion needs and actual local practice. We do not have Folk High Schools as in Sweden; there is no "global intervention", no "communication ramps", and no “inclusion”.

Inclusive education is a complex issue concerning not only the education of a special group but the education of all learners and not only the maintenance of students with disability in any learning experiences but also the optimization of their participation:

"*So, inclusion is not about assimilation or accommodation of individuals into an essentially unchanged system of educational provision and practice. It is not fundamentally concerned with the inclusion of categorized pupils such as disabled pupils. It is more than this. It is not about placement or the removal of an individual from one context into another. It is not about dumping children into what are essentially extensions of their former segregated experiences. Inclusive education is not about the reform of special education nor is it a sub-specialism of special education. Inclusive education is about why, how, when, where and the consequences of educating all learners. It involves the politics of recognition and is concerned with the serious issue of who is included and who is excluded within education and society generally*[40]*".*

Inclusion guarantees the rights to social participation and this objective includes, necessarily a change in the educational approach and the creation of educational agencies aimed at offering the support that has been demanded from medical doctors until today.

[40] Inclusive education and teacher education A basis for hope or a discourse of delusion. Len Barton , 2003 by the Institute of Education, University of London

Moreover medicine has showed to be unsuitable to manage the complexity of aphasia. It is demonstrated by the irrelevance, discriminatory and exclusionary features of current Italian provision and practice in rehabilitation versus people with aphasia[41].

[41] Speech Therapist seems to be the only reference for "inclusion" of the aphasic person in the social and professional context but we know that aphasia involves - since the beginning - emotional, behavioral and social aspects therefore medical skills are not enough.

CHAPTER 2
THEORETICAL FRAMEWORKS

Learning

Regarding the concept of learning, we refer to the common definitions, trying to apply them to an aphasic target.

Learning can be defined as "the cognitive process of acquiring skills or knowledge through study, experience or teaching" and also is "a change in neural function as a consequence of experience".

Therefore when there is learning, there is a relatively permanent change in cognition that results in improved performance over time on tasks similar to those done previously. It directly influences behavior that can be physical and overt, or it can be intellectual or attitudinal.

At this regard, there are many theories (for example behaviorist, cognitive, humanist, and constructivist), to explain

how one learns[42] and in particular how adult learn differently from children. When adults become aphasic, their perspective on the learning process remains an adult one. Then, the needs to reestablish old behaviors and to learn new skills are superimposed on adult perspectives and, for adults, it is not sufficient to make one experience in order to learn.

If we consider the Kolb Experiential Learning Cycle, we see that the learner must link theory action by reflecting and relating it back to theory. This can be "cognitive-consuming" for a person with brain damage.

In this context, two important conceptual frameworks are *andragogy* and *learner centered principles*.

[42] Merriam SB, Caffarella RS. Learning in Adulthood. 2nd ed. San Francisco, Calif: Jossey-Bass; 1999

The contribute of andragogy

Andragogy is a term that was originally coined in the United States by Malcolm Knowles[43] in the late 1960s, defined as the "art and science of helping adults learn," and is a model based on a set of assumptions about adult learners that differentiate them from children and pedagogy. Before formulating his theory, he was first interested in adult informal education in which a 'friendly and informal environment' gives the possibility to learn to *every* adult through the flexibility of the process, the use of experience of the learners and the enthusiasm of participants.

I have selected key principles from several frameworks on Knowles 'assumptions, that are relevant to our work and I tried to apply them to an aphasic target.

[43] Knowles, Malcom (1984). Andragogy in action: applying modern principles of adult learning. San Francisco: Jossey-Bass.

BASIC PRINCIPLES OF ADULT LEARNING
Adults maintain ability to learn
Adults are a highly diversified group of individuals with widely differing preferences, needs, backgrounds, and skills.
Adults experience a wide variety of physical/sensory capabilities.
Experience of the learner is a major resource in learning situations.
Self-concept moves from dependency to independency as individuals grow in responsibilities, experiences and confidence.
Adults tend to be life-centered in their orientation to learning.
Adults are motivated to learn by a variety of factors.
Active learner participation contributes to learning.
A comfortable supportive environment is a key to successful learning.

Adults maintain the ability to learn in a wide variety of physical/sensory capabilities. And I suggest "also in aphasia". I believe it, clearly not if there are other severe cognitive deficits accompanying aphasia, but if we trust in the approach of Aura Kagan, the aphasia masks the ability of the subject to participate in a conversation, and therefore masks also the possibility to learn in a formal educational setting.

Adult learners tend to be life-centered in their orientation to learning and are motivated to learn to the extent that they perceive that it will help them perform tasks they confront in their life situations. If the adult is an individual with aphasia who has recently acquired the disability, we can assume that he/she will be oriented to restart to speak "like before". We can assume also that he/she hopes to reach this goal through educational activities very similar to the ones he/she carried out as a child (traditional rehabilitation). After a while it is possible that the individual, especially if developing a process of identity re-negotiation, will discover his/her need of "real" educational contents (beyond the general and often utopian idea of improvement of language functions) to be included in a real context of programming of personal and professional life.

In this context it would be necessary that the professionals surrounding people with aphasia (therapist) acted like "learning facilitators", helping their patients to Freire[44]'s *awakening of awareness,* using arguments like the value of

[44] For Freire, Educação como prática da libertade. Rio de Janeiro, Paz e Terra, 1967, education is a process of development and empowerment, involving stages of awareness and transformation. It combines the assets of reflective practice with those of socio-cultural theories and goes further, highlighting the importance of situating the learning within the context of the learner and of the agents and institutions of learning, constantly reflecting on them.

learning in order to improve their performance at work or in their personal life. A further difficulty comes from the fact that people with aphasia are adults who have a developed sense of self and responsibility for their own lives[45]; nevertheless they are often affected by former rehabilitation experiences in which the student plays a passive role in the educational activities entirely coordinated by the "teacher". One of the main and more demanding tasks of the educator will be to stimulate people with aphasia to take their own decisions about what they will do, including what they will learn. They need to be treated as capable of self-direction. So, it is important to analyze question relating educational programs designed around dependency and directedness, precluding consideration of the thoughts and experiences of the learner. Respect the matter of instructional situations, an important theoretical framework is supplied by Pratt[46] (Fig.1), based on direction and support needed by learners.

[45] Knowles M, Holton EF, Swanson RA. The Adult Learner: The Definitive Classic in Adult Education and Human Resource Development. 5th ed. Houston, Tex: Gulf Publishing Co; 1998

[46] Pratt DD. Andragogy as a relational construct. Adult Educ Q. 1988;38(3):160-181

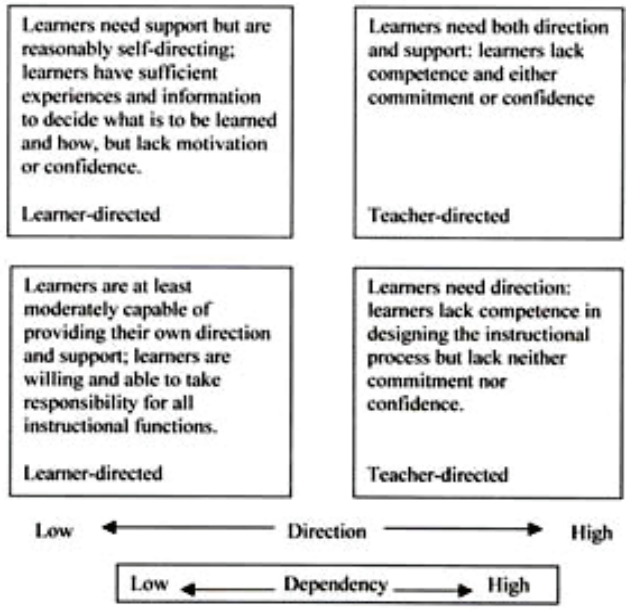

Fig. 1

In the 4 quadrants of this model, Pratt describes the learner's competence in deciding what to learn, how to learn it, and the confidence and commitment needed to carry out the process. Amount of direction needed from the teacher and dependency on the teacher range, on a continuum of low to high. Learners may need direction in deciding what and how to learn as well as some support in the process, in which case the learning situation would be teacher-directed. If the individual is relatively capable of self-direction and support, the learning

situation would be primarily learner-directed. As we will see, direction alternated with complete autonomy in managing the educational process, it is an important topic for learners with aphasia. The focus of the problem is the share of necessary support to students with aphasia as next experience demonstrates (see Chapter 3).

All learning begins with experience[47] and this statement may be particularly important in discussions on adult learning. Adult learners have a variety of experiences which represent the richest resource for learning. An off-quoted characteristic of older adults is that they are a heterogeneous group[48] compared to other age ranges, particularly children[49]. This heterogeneity is the direct result of a lifetime of accumulated experience that differentiates one individual from another[50]. As Merriam and Cafarella note "experiences are never just isolated events in time. Rather, learners must connect what

[47] Jarvis P. Adult Learning in the Social Context. London: Croom Helm; 1987

[48] A group of 60 years old will have less in common than a group of 20 year olds (Merriam SB, Caffarella RS, Learning in Adulthood. 2nd ed. San Francisco, Calif: Jossey-Bassa; 1999

[49] Knowles and colleagues state that "to children, experience is something that happens to them; to adults, their experience is who they are".

[50] Knowles M, Holton EF, Swanson RA. The Adult Learner

they have learned from current experiences to those in the past, as well as see possible future applications". So, prior experience is an important yet under-recognized contributor to the success of learning for adults and provides a rich context in which to embed learning activities. We have to remind it also when we propose to aphasic people a therapy experience in which previous life experiences should be utilized to promote learning at the behavioral and physiological levels. Clinicians can design therapy programs that draw on individuals' experiences and interests, selecting tasks, stimuli, and outcomes that have immediate relevance to the client and coincide with their previous experiences and future goals. But when clinicians (especially those who are recognizably much younger than their clients) act as teachers, directing much of the learning process in terms of goals, techniques, and stimuli, older adult clients may feel as if they were incapable of self-direction. The result will be resentment and resistance. In addition, if the learning process is clinician-constructed and driven, it may be designed around problems that are unimportant[51] to the learner. It is necessary, therefore to revisit

[51] For example, including symbols for toilet, water, and food in communication books is a common practice of speech-language pathologists, yet these symbols may rarely be used by individuals with aphasia, whose communication needs relate more to socialization than basic activities of daily living.

the educational proposals which have no link with the previous experiences of the individual, all-inclusive offers that have more to do with entertainment than with education.

All students, regardless of age, need a comfortable supportive environment for learning. Adults need help in overcoming their insecurities, and they need much praise and encouragement especially if they have already experienced the interaction difficulties subsequent the disease and the devastating effect of an insensitive and inaccessible world responsible for a sense of inability and incompetence (constructed incompetence)[52]. The educative program has to do with the development of the learner's sense of competence. So it could be important to use feedback types to assert competences. On the other hand the growing competence of self-evaluation helps students to become more responsible in facing problems and solving them. Self-evaluation helps learners to think more independently and act resourcefully.

As for supporting environment, a sensory-enriched environment enhances positive attitudes and behavior, above all in the case of disabled learning. Students exposed to

[52] Constructing (in)competence: Disabling Evaluations in Clinical and Social interaction. Dana Kovarsky, Judith F. Duchan, and Madeline Maxwell, Lawrence Erlbaum Associates Publishers, 1999

enriched environments can perform tasks significantly better than those exposed to less stimulating environments. An enriched environment has a certain number of characteristics able to promote the development of a broad range of skills and interests that are mental, physical, social and emotional. A learning atmosphere must be created to reduce pressure and stress by blending work with enjoyment, positive emotional support and promotion of exploration and the fun of learning.
Regarding the concept of supportive environment, we can find some suggestions in a Worral's study about the Environmental factors that influence the community participation of adults with aphasia[53]. Some categories of barriers and facilitators are: people environmental factors (lack of knowledge and misassumptions, negative attitudes, strategies used by individuals), and physical environmental factors (these included the use of written information, the use of technology interfaces, auditory factors).

Adults are motivated to learn by a variety of factors. The readiness or motivation to the learning process is a really important factor, a driving force in the cognitive process, as it

[53] Environmental factors that influence the community participation of adults with aphasia: The perspective of service industry workers, Brown, Kyla et al. Aphasiology, Volume 20, Number 7, July 2006, pp. 595-615(21)

influences how and why one learns and fosters thinking and attention. Theories that specifically examine motivation in adult education are usually based on general motivation theories according to which human beings cannot effectively think about an issue or learn something that is considered boring or useless. The educative program should be focused on tools capable of facilitating motivation and arousing interest in students, thus promoting learning. To motivate is to "make somebody want to do something, especially something that involves hard work and effort"[54] . And so the question arises as to how teachers or clinicians can induce motivation in their adult clients[55]**.** Knowles and colleagues comment that adults are ready to learn when they need new knowledge or skills to cope with real-life situations. Anyway motivation is seen as something residing primarily within the individual, for example Wlodowski[56] states that adults' motivation to learn is the sum of 4 factors: success (adults want to be successful learners), volition (adults want to feel they have a choice in

[54] Brown L, ed. The New Shorter Oxford English Dictionary: On Historical Principles. New York, NY: Oxford University Press; 1993

[55] In their work within the domain of corporate learning and education, Swanson and Law reported on the Whole-Part-Whole Learning Model that may help increase motivation or readiness to learn in adults.

[56] Wlodowski RJ. Enhancing Adult Motivation to Learn. San Francisco: Jossey-Bass; 1985

their learning), value (adults want to learn something they value), and enjoyment (adults want the learning experience to be pleasurable). However, clients may lack the commitment or the motivation to learn, despite the need for new knowledge or skills following stroke; clinicians frequently speak of a client's motivation to learn or participate in tasks, citing the presence or absence of this trait as a facilitator or barrier to therapeutic progress[57] (like insufficient self-confidence). However, also in this case there is someone who considers the different option in which motivation is a construct of those who see it lacking in others:

"A critical reading of the literature shows how motivation theory stigmatizes people held 'unmotivated' in that the theories ascribe motivation problems to the individual, while assuming the basis upon which the problem is formulated for granted, and making those who formulate the problem invisible. Instead of a problem solver, motivation becomes a euphemism for direction and control (...) motivation should be seen as a relational concept, rather than as residing within the

[57] Rehabilitative therapy requires hard work, but it should also promote success and enjoyment through the learning of meaningful, relevant knowledge and skills. The individual with aphasia must become a "mutual partner" in the learning process, rather than the passive recipient of a therapy service (Merriam).

individual. Adults' motivation, or lack of this, is best understood in relation to those who formulate the problem. Instead of asking what motivates adults to study, research should focus on who states that this is a problem, and why, and the reasons for this conclusion"[58].

Also in this case, the approach makes the operations of power visible, and demonstrates how the discourse of lifelong learning, as a necessary political response to economic and technological determinism, constructs adults as inadequate.

This is, briefly, the andragogy's contribute, but when focusing on adult students, it is crucial to consider also other substantial theories in learning.

A constructivist learning environment

An effective and useful pedagogical approach for adults is the *constructivist*[59] one, derived from a theory of cognitive growth

[58] Helene Ahl. Motivation in adult education: a problem solver or a euphemism for direction and control? Int. J. Of Lifelong Education, vol. 25, no. 4 (july-august 2006), 385–405.
[59] Constructivism is an alternative epistemology of how people learn and assimilate new knowledge

and learning that centers on the individual and creates learning experiences and tools. Humans are active, knowledge-searching creatures that transform and interpret experience using developed biological and mental structures. They assimilate new knowledge by producing cognitive structures that are similar to the experiences they are engaged in. These newly developed knowledge structures are used within their collection of experiences as they continue to interact with the environment. Knowledge is not separate from but rather embedded within experiences and interpreted by the learner. Knowledge then is about interpretation, and giving meaning to the environment. In other words, though we may more or less share one reality, each of us conceives of it in different ways based on our prior experiences, belief structures and perspective. Learning, therefore, is communicating and demonstrating understanding of the world. From this point of view, interpretation constructivism can include different types of knowledge construction than rote memorization of factual knowledge or procedures. The goal for the learner is to build, or re-invent knowledge.

A constructivist system stresses the following functions:
• emphasis is on knowledge construction rather than on its reproduction;
• the learning process is a student-centered one;
• teachers are facilitators of learning;
• meaningful and relevant learning is enhanced;
• educational goals that are consistent with learners' goals are elaborated;
• learning tasks that are embedded in authentic contexts are proposed;
• collaboration is encouraged;
• meta-cognitive and reflexive activities are promoted.

A constructivist learning environment is an environment where learners collaborate and support each other using a variety of tools and resources. It is an environment where knowledge is constructed and learners assume a central role in the cognitive process. In fact, this approach has some main principles: learners are creators of knowledge; namely, they actively construct their knowledge while not simply[60] absorbing ideas presented by teachers through repeated practice, but developing thoughts and actions.

[60] In learning process, learners assimilate new information connecting them to pre-existing notions and modifying their understanding through this connection.

A learner - centered education framework

In an education setting oriented to people with aphasia, it is fundamental to adopt a Learner-centered education (LCE), a pedagogical framework that positions learners at the center of the instructional process, not as passive recipients of information like in the traditional teacher- or content-centered approach. It begins with understanding the original educational contexts of the student and it continues with the instructor evaluation of the student's progress towards learning objectives. It places the responsibility for learning on the student, while the instructor assumes responsibility for facilitating the student's education. This approach strives to be individualistic, flexible, competency-based, varied in methodology and not always constrained by time or place.

An interesting experience in which having considered the objectives of adult students has improved the learning of caregivers, is the program by Riva Sorin Peters[61] in which have been included the self-concept of adult learners and their prior experiences.

[61] Sorin-Peters R. Development and evaluation of a learner-centered training program for spouses of adults with aphasia. Aphasiology 2003:17(4):405-416.

A learner-centered training program for spouses of adults with chronic aphasia (by R. Sorin-Peters).
A training program for partners of adults with aphasia was developed cooperatively by the clinician, the individual with aphasia, and the family. The goals were developed in the context of everyday life needs, and the success of the program was evaluated by all participants. The process began with interviews concerning what problems were viewed as priorities for treatment. The clinician operationalized these into clinical tasks with input from the individual with aphasia and the family. Then, the tasks were practiced in the appropriate contexts to ensure their relevance to the client. This type of approach is grounded in adult learning principles and demonstrates how adhering to these principles may increase adults' motivation to participate in educative programs.

The learner-centered environment facilitates the exploration of meaning and content through personal and interpersonal discovery and from this point of view coincides perfectly with the needs of the individual with aphasia of re-structuring their own life re-negotiating new meanings. Learning is particularly effective when students work together towards a common goal and are engaged in real argumentative situations.

Therefore people with aphasia, as other adults students, should be part of negotiations to achieve a shared solution. In order to achieve this result, cooperative learning methods and the

Examples of learner-centered educational practices
• Collaborative group learning, both inside and outside the classroom;
• Individual student research and discovery;
• Research and discovery by students and faculty together;
• Problem-based inquiry learning;
• Student-faculty studio and performance activities;
• Asynchronous distance learning;
• Synchronous interactive distance learning;
• Service learning activities;
• Hands-on, experiential learning activities;
• On-site field experiences;
• Self-paced tutorials.

capitalization on learners' prior experiences are indicated. There are different ways: it is possible to use structured teaching-learning situations such as those that occur in the classroom (for example, experiential techniques, group discussions and case study) or to use new modalities and technologies that can greatly improve the efficiency exhibited by students in acquiring new skills and knowledge. They are

experiences successfully applied in ACTIVE project[62] financed by the EU Commission, whose target group was composed of people with aphasia After analyzing the theoretical references in order to detect the key points of the difficulties and the success of the learning applied to people with aphasia, we have to consider the real experience of the participants. The learners' point of view is in fact fundamental because people who are involved in the education process are in the best position to understand and to describe their experiences and needs.

[62] F. Colace, M. De Santo, M. Vento. "E-Learning Platform: Developing an Evaluation Strategy in a Real Case". Proceedings of IEEE Frontiers In Education , Indianapolis, pp. 20 - 25, 2005.

CHAPTER 3
LEARNERS POINT OF VIEW

A concrete experience

Very few studies have reported the opinions of disabled students on their experiences in further or higher education and their perceived learning needs. The perspective of students with aphasia on these issues is even less well documented.

We are now going to analyze one of the few available studies on perceptions of students with aphasia and tutors in further education[63]. It uses qualitative research methods to capture issues important to the participants in teaching and learning, by interviewing both students and their tutors. Two women with aphasia and four of their tutors completed a questionnaire and/or were interviewed in order to obtain a detailed account of their perceptions and experiences of further education, with particular emphasis on how the students managed and what the tutors did to help. The analysis of some parts of the article will allow the identification of useful strategies and behaviors to

[63] 'Helping or something': perceptions of students with aphasia and tutors in further education. Bruce C, Parker A, Renfrew L. Int J Lang Commun Disord. 2006 Mar-Apr;

decrease difficulties.

"Several studies that have interviewed students with disabilities reveal that finance, transport and physical access are barriers to further and higher education (Borland and James 1999, Poussu-Olli 1999). Some disabled students in further education have personal assistants to help them carry out personal and academic tasks. These assistants enable access to Higher Education for those students who would otherwise be excluded, and increase access to the curriculum for others. The benefits for the students are obvious. However, this essential support may also bring other challenges. Research suggests that disabled students requiring this assistance may encounter other barriers that prevent them from participating fully in the educational experience. The presence of an intermediary sometimes interferes with the students' ability to develop relationships with their peers (Parker 1999)[64].

This last aspect is particularly important in a context which is very likely to underestimate the students' competence because of both the stereotypes and real difficulties of accessing

[64] ibidem

independently to complex communication contexts.

"The drawback of having a personal assistant that inhibits the development of a disabled student's social life may be outweighed by the gains, and many students with aphasia may seek this type of support. At present, disabled students are usually expected to take responsibility for hiring and managing their personal assistants. This process is likely to be particularly demanding for a person with aphasia"[65].

An eventual failure may result in stigma of incompetence that conditions the possibility to live the experience in a global and satisfactory way. The concept of stigma and ignorance of the difficulties experienced by people with aphasia is among the additional barriers that prevent access to broader curricular and social experiences[66]. A number of studies acknowledge the importance of positive attitudes amongst staff in facilitating social inclusion and increasing participation in education.

"For example, the expectations of academic staff and other

[65] ibidem
[66] Communication access to the arts. J. Duchan et al. Topics on Language Disorder, 2006, 26, n° 3, 210-220

students were often found to contribute to the discrimination experienced by disabled students. Good lines of communication between staff, and staff and students are reported to be essential. Negative experiences are more likely to occur when staff is unaware of or uninformed about the student's disability and the support available. Unfortunately, students with aphasia are likely to find themselves in this situation"[67].

An international face-to-face survey[68] of individuals in public places found that there was a general lack of public awareness of aphasia in England, the USA, and Australia[69]. Obviously this public awareness can affect also the accessibility to educative experience for people with aphasia.

"Moreover, in one of the few studies that specifically

[67] 'Helping or something': perceptions of students with aphasia and tutors in further education. Bruce C, Parker A, Renfrew L. Int J Lang Commun Disord. 2006 Mar-Apr;41(2)

[68] Simmons-Mackie N, Code C, Armstrong E, et al. What is aphasia? Results of an international survey. Aphasiology 2002; 16: 837-48

[69] A total of 978 individuals were surveyed and data were analyzed to determine the number of informants who had "heard of aphasia" and the number with "basic knowledge of aphasia". Of the individuals surveyed, the 13.6% said they had heard of aphasia, but only 5.4% met the criterion of having "basic knowledge of aphasia".

mentions aphasia, one man who was interviewed reported that the non-completion of his course was in part due to his tutor's failure to understand the implications of aphasia and what could be done to help (Parr et al. 1997). The authors state that, as many tutors will be uninformed about aphasia, it is likely to be incumbent on the student to explain his or her needs. The public's lack of awareness is compounded in higher education by the fact that the impairment-focused classification system used by the Universities Central Admissions Service does not include aphasia"[70].

In Italy, according to the Law 104/92 and its subsequent alterations and changes, particularly with the Law 17/99, many universities have promoted projects aimed at the inclusion of disabled students, which include the providing of Tutors and specific educational devices. However the considered disabilities (physical or sensorial disability) do not include aphasia. Some projects consider the problems related to dyslexia[71], proposing solutions that would be useful also for students with aphasia (diagnostic test, entry test for students

[70] 'Helping or something': perceptions of students with aphasia and tutors in further education. Bruce C, Parker A, Renfrew L. Int J Lang Commun Disord. 2006 Mar-Apr;41(2):137-54.

[71] Dyslexic students in the recent past had to give up studying after the mandatory education, now the demand support from university professors.

declaring to be dyslexic, computer entry test and exams using vocal synthesis devices, oral exams instead of written exams, tutoring, and study groups). Many suggestions that are listed for other disabilities might well be applicable for students with aphasia, on the other hand there is a lack of recognition that aphasia exists.

The problems are mostly tied to the difficulties of accessing to some kind of efficient support and tutoring because of:

- difficulties in explaining need,
- a lack of awareness for both parties of the real difficulties caused by aphasia
- a need for ongoing feedback in the system.

"Accessing learning support is partly dependent on how much the student is able or willing to divulge about individual needs on the course. Research has shown that students differ in their willingness to seek support "[72].

The students could be unwilling to disclose information. Some of them show independency to avoid a label of disability. Again some could find it difficult to explain their difficulties

[72] 'Helping or something': perceptions of students with aphasia and tutors in further education. Bruce C, Parker A, Renfrew L. Int J Lang Commun Disord. 2006 Mar-Apr;41(2)

because of their non full mastery of the language and the complexity of the speech. Sometimes they are not completely aware of the way language difficulties affect their attendance of an educational course.

"Without a clear understanding of the nature of aphasia and an ability to converse with a person with communication difficulties, staff will not be able to facilitate full disclosure of needs on entry to the course. The two women in this study were able to identify their areas of difficulty when provided with a list of skills that might be needed for further education[73]*".*

This is the first suggestion about the disclosure process; this could be enhanced by the provision of a checklist of skills for each proposed course and it suggests that the process of securing support might also benefit from the presence of an advocate or facilitator. An interesting element concerns the different perception of the provided support, insufficient according to the female students with aphasia and efficient according to the tutors:

[73] ibidem

"This finding highlights the importance of systems that allow continuing discussion of students' needs, and more formally agreed arrangements so that both parties are aware of what is provided. A recorded agreement, communicated with the student's permission to relevant staff, may also help with problems of different assumptions related to confidentiality"[74].

It is important to consider that we are relating to active and interactive adult subjects, also concerning the diagnostic element, with needs of privacy and discretion.

"One way to circumvent the possible conflict would be to ensure that these issues were discussed at the outset and an understanding reached of what has been agreed regarding confidentiality and disclosure. Thus, students who wish to keep the whole responsibility for managing access to learning will be clear about the need to decide individually about disclosure to relevant staff, while others will know that the department has informed those who need to know. An agreed statement of requirements, based on a checklist such as that mentioned above, and regularly reviewed, would provide support for the whole process"[75].

[74] ibidem
[75] ibidem

It is so far clear that the aspects concerning openness and awareness of one's own potential and weakness is a critical factor for the re-inclusion in the professional life of the individual and should be supported by rehabilitation professionals.

"The onus on the students to explain the nature of their difficulties could have been reduced by the speech and language therapist's report"[76].

Therefore a partnership between Speech Language Therapist and academic staff is to be supported; in this context the speech therapist can promote learning and facilitate inclusion, helping to raise understanding and awareness of aphasia in the staff responsible for the admissions procedures, teaching and assessment.

Moreover speech therapists could improve the provision of appropriate support for students with aphasia in further education according to the difficulties[77] which are not commonly considered in the documentation provided for university comities.

[76] ibidem
[77] i.e. the word finding difficulties, or the increased fatigue

Bruce et al. discuss the issue concerning the role of the Speech Language Therapist in the educational field:

"Is it the knowledge about aphasia and its consequences or the language skills that the Speech Language Therapist will have used that helped? It is possible that this training would have been even more successful if delivered by a tutor who was aware of the nature of aphasia"[78].

[78] ibidem

CHAPTER 4
LEARNING IN REHABILITATION CONTEXT

Conflicting Views

We have focused on the need of the active role of the rehabilitation operator, considered as the "facilitator" of the learning process for people with aphasia. From now on, the issue concerning the direct or indirect relation between learning process and rehabilitation is to be considered.

On the concept of learning inside the rehabilitation context, a vast literature, constantly supporting the similarities between therapeutic relation and pedagogic relation[79], has been produced from the'50s[80] until today[81].

According to Wepman, the person with aphasia must re-*learn* old skills and new adaptations by building a gestalt and not

[79] it opens to "rehabilitation" even if it is not part of LAPH project.
[80] Recovery From Aphasia by Wepman, Joseph M., The Ronald Press Co., 1951.
[81] Hopper, Tammy PhD; Holland, Audrey L. PhD Aphasia and Learning in Adults: Key Concepts and Clinical Considerations. Topics in Geriatric Rehabilitation. Educational Intervention. 21(4):315-322, October/December 2005

through word drills or vocabulary building. Hence the need that Aphasia Therapist[82] plays an educational as well as therapeutic role (the author suggests to avoid traditional educational methods such as the subject-matter-centred education).This need is confirmed by researchers such as Hopper and Holland who consider learning central to the therapeutic action, because it is the principal mechanism for the acquisition of new skills and behaviours, for relearning components of language, for learning new compensatory strategies and for helping communication partners to "unmask" language competence still intact in individuals with aphasia[83]. Understanding the context in which adult learning is facilitated, and integrating principles of adult learning into treatment are tangible ways to ensure empowerment of the patient in the therapeutic enterprise. A vast literature related to learning theory exists, and some writers have discussed how to apply learning theories to aphasia therapy[84]-[85]. In my opinion, learning theories are at the basis of enactment process of many

[82] corresponding to the current Speech Language Therapist

[83] Kagan A. Revealing the competence of aphasic adults through conversation: a challenge to health professionals. Top Stroke Rehabil. 1995;2(1):15-28

[84] Ferguson A. Learning in aphasia therapy: it's not so much what you do but how you do it! Aphasiology. 1999;13(2):125-132.;

[85] Sorin-Peters R. Development and evaluation of a learner-centered training program for spouses of adults with aphasia. Aphasiology 2003:17(4):405-416.

rehabilitative therapies, providing reference frame to the therapeutic intervention (in theory, learning methodologies allow the Speech Language Therapist to "handle" the situation in order to realize the rehabilitative goals, allowing the integration of affective, cognitive and behavioral learning...). On the other hand the relation between the theory of impairment/disability and the learning theories is not direct. Moreover we cannot take the connection between pedagogic relation and rehabilitative relation for granted; the objective of aphasia therapy does not in fact consist in teaching something but rather in supporting the re-activation of inhibited abilities, the re-organization of the remaining abilities and the development of compensation strategies.

Still, if the relation between rehabilitative and pedagogic interventions is so clear, how can we explain the therapists lack of knowledge in matter of learning theories (at least in Italy)?

The role of the rehabilitation professionals has changed and the education of patients and families has become even more important as reimbursement has declined. With fewer visits, therapists must be certain that patients understand their home programs and that family members can comfortably assist. On

the other hand, while master clinicians have the clinical expertise, they often lack in the theoretical understanding and skills related to the educational process. Often, they have had little or no exposure to educational principles, they don't have advanced skills in educating patients, support-personnel, and providing in-service education, they are not able to compare different learning approaches, different teaching and learning styles, they don't know theories of adult learning and development, needs assessment, program development and assessment, curriculum development around competency-based testing, development of educational materials for the classroom, theories of education, nor they have hands-on experience in laboratory and classroom teaching.

Still, in theory, rehabilitation should be considered complete by the time people with aphasia are ready to consider the possibility of entering further or higher education. Often instead, the rehabilitation process is seen by relatives as complete 'when minimal function is regained and is insufficient in duration or scope to prepare people for work after stroke'.

Perhaps we should think of involving the teachers in rehabilitative settings or, as suggested before, of creating partnerships between teachers and therapists, following the

example of speech therapy for children?

Rather than assimilating therapeutic setting and pedagogic action we should reflect on the fact that adult education classes are a potential source of language work[86] and that the therapist educational action is evident in a different situation, when he/she educates patients and families about their conditions or he /she is involved in the clinical education of future rehabilitation providers. At this point, once again, we suggest the analysis of Education Principles into Rehabilitation by Riva Sorin Peters which we have briefly described without the possibility of an in-depth analysis which I highly recommend (this work does not concern the educational role of the therapist but rather the role of Learner of the person with aphasia).

As for the Italian situation, the lack of connection between education and rehabilitation creates obstacles to further education for people with aphasia. They should be able to ask specialists for support and help as their circumstances and needs change. In some cases this might mean support from ongoing Speech Language Therapist involvement, in

[86] Jordan L & Kaiser W (1996) *Aphasia – A Social Approach*. London: Chapman & Hall.

partnership with the educational agencies, as demonstrated by the experience carried out between '81 and '83 by Adult Literacy and Basic Skills Unit as a part of the project aimed at developing educational provision for aphasic people and by a recent initiative in Italy – the first one of the kind – concerning the collaboration between users of the speech Therapy Service of ASL7 in Settimo Torinese and the Permanent Territory Center for Adult Education and Training in Settimo Torinese[87].

These types of experiences confirm the value of the involvement of new professionals, then the traditional rehabilitation professionals in the re-educational field. A teacher, in fact, has the big advantage of being free from prejudices about "that" particular ailment; he/she will not be eager to label any single evident sign and will therefore *really* follow the educational needs of the subject. Speech Therapists rarely go beyond their "normative" role.

On the other hand we have also to consider the problems, concerning roles, highlighted by the experience. In this type of collaborations tensions and conflicts often appear (from

[87] A mixed literacy course has been organized. There are foreign citizens as well as individual with aphasia, both groups are very satisfied.

leadership to pattern of cooperation level[88]).

To solve this problem specialized trainers are needed, according to what Riccardo Massa defines "Clinic of Formation". They are education professionals who, mastering their different educational tools, are prepared to solve their students' problems[89] related to their own or other's emotions and feelings.

In this context it is also necessary to consider the need of a common language between the two fields (education and rehabilitation). C. Bruce, discuss on the value of using, for this goal, the ICF's framework.

[88] They discussed about who had to decide the discharge, according to the educators the subject itself.

[89] It is not granted that teachers or rehabilitation professionals have the emotional maturity to be in charge for their students' emotional problems.

CHAPTER 5
EDUCATIONAL RESOURCES FOR SPECIAL NEEDS

Can ICF reduce complexity?

"The importance of recognizing the effects of the individual's level of functioning is borne out by the students reporting concerns about the learning issues associated with aphasia, and the tutors expressing a need to know more about the nature of the problem…"[90]

The International Classification of Functioning, Disability and Health[91] seems to be the ideal tool to examine the complex interplay of the individual with aphasia and the education environment.

[90] 'Helping or something': perceptions of students with aphasia and tutors in further education. Bruce C, Parker A, Renfrew L. Int J Lang Commun Disord. 2006 Mar-Apr;41(2).

[91] L'ICF helps to define the different special educational needs, some of them characterized by biological problems or concerning the personal activities, others have environmental or social problems, etc

In Italy in 2006 an interesting study has been carried out[92] through ICF classification on a population of 100 disabled[93] university students. According to the study the disabled students' performances have decreased in the university. This seems to be caused by both functional/structural characteristics of the sample and the presence of particular environmental barriers. The study confirmed that using ICF it is possible to obtain a detailed overview of all the factors concurring to determine disability suggesting, where it is possible, the interventions and the policies to carry out. Finally, according to the authors, through the application of the ability and performance qualificators of ICF system to the collected data, it is possible the diachronic monitoring of the adopted policies, adjusting and improving them when necessary.

Hence the anthropological model of human functioning proposed by ICF represents a common language as well as a good conceptual model of "special educational needs[94]" of disabled. The question is, "is it necessary to use the adjective

[92] By Gaetano Romagnuolo, Carmine Rizzo and Paolo Valeri, carried out in the field of the activities of Specialized Tutoring Service, Federico II of Napoli, promoted and coordinated by Commission for the inclusion of Disabled University Students and by Specialization School of Clinical Psychology.

[93] The sample has severe neurosensorial and movement disabilities

[94] Educational special needs are originated by a wide range of unfavourable conditions which ICF is able to systematize.

"special[95]" or it would be better to talk about "particular educational needs" or "specific educational needs"?

According to Dario Ianes "we have to go beyond the negative perception of "special" considered as discriminating and denigrating and re-evaluate the adjective "special" as richer and more powerful."[96] Still, ICF includes an individual functionality continuum on which we will have to express a judgment of non-functionality. Is it coherent with what we have stated until now about inclusive philosophy? We have supported the necessity of activating all the resources for inclusion enlarging the concept of resource and including in it also aspects of the educational community which were not traditionally included. Does the utilization of a system which creates codes and labels take us away from the fundamental concept of inclusion? It is important to remember the perplexities expressed by J. Fleson Duchan[97] when stating that if we use the ICF to carry out all aspects of clinical practice "we could lose sight of the person" since the ICF model creates a blind spot for the person's subjective experience.

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[95] According to international literature and rules. (Special Education).

[96] Dario Ianes, Bisogni Educativi Speciali e inclusione, pp. 287, € 18,50, Erickson 2006

[97] Where is the person in the ICF? Author: J Felson Duchan. Source: Advances in Speech Language Pathology, Volume 6, Number 1, March 2004, pp. 63-65(3)

"We would be more likely to treat the person with a disability as someone with a codable condition rather than as a human being who experiences that condition"[98]

A Narrative Approach: implications for Adult Education

In my opinion, ICF, which is projected towards a social model, does not completely succeed in reaching its target; it results something between the social model and the medical model represented by the former (ICDH), from which ICF derives. In this sense, I can only see it in a critical way, in the frame of the ideological (epistemological post-rationalist) reflection that I am personally making in the LAPH Project.

Hence the suggestion of different methods aimed at emphasizing the individual experience and point of view. Only in this way we can identify the key points of the success of the educational intervention.

[98] ibidem

"the most relevant approaches for revealing and emphasizing a person's life experiences are ones that are grounded in narrative discourse. Personal narratives are, for many, the best means to convey and understand a person's life experiences. (...) First-person narratives are typically told from the point of view of the patient, client or student."[99]

There are undeniable advantages in the use of ICF for some situations. However, personal narratives are much more efficient from an educational point of view; besides, the narrative and autobiographic approaches are useful in all situations of re-construction of life pathways. Starting from these considerations and being aware that collective memory is part of the public good belonging to a "competent" community which takes care of itself and of its members, in 2005 we launched the Autobiography Project and the Wonder Room[100] in the context of Italian Group Studies on Aphasia[101].

[99] ibidem
[100] It is an attempt to collect and organize, through methodologies tied to the autobiographic approach, and with a participative method, a new collective memory on aphasia which can become a public good accessible to all www.aphasiaforum.com/autobiografia.htm).
[101] www.aphasiaforum.com/gruppostudio.htm

CHAPTER 6
COOPERATIVE AND ACTIVE LEARNING

Learning, identity and interaction

In the previous paragraphs we have carried out a deep reflection on the whole process of learning and teaching, rethinking education from the learner's perspective. We have seen how moving from a behaviorist to a constructivist paradigm, educational research changes from a transmission-model that emphasizes teaching methods to one that is active, exploratory and learner-oriented. But, first of all we have discussed the need of a global approach on learning which has to be founded on the holistic consideration of the individual as a unity of body/mind, affectivity/relation; this is an important topic for a community that risks the "identity fragmentation". There is the need to identify the suitable contents for the expression and the integration of different aspects[102] of the person (regardless disability but more needed in case of relational difficulties). There are environments more suitable than others to stimulate the learning potential of the students

[102] This datum is confirmed by the Theory of plurality of intelligence by Gardner

with aphasia. I think the best place to re-negotiate identity through learning of new "selves" and new "roles", is the Laboratory[103], which differently from the classroom where students "use" the educational contents; it is very useful also for the integration in the social group. We can consider this context as an example of active and cooperative, even if informal learning.

In fact, active learning is a learning environment that allows "students to talk and listen, read, write, and reflect as they approach course content through problem-solving exercises, informal small groups, simulations, case studies, role playing, and other activities -- all of which require students to apply what they are learning".

We consider as informal environments those contexts where we can find a really transformative and respectful pedagogy, which supports development of a free and harmonic personality. Can we say the same of certain impairment-based rehabilitation or, rather, it limits the individual development through referring continually to rules? Does a rehabilitation session create harmony in the life of the individual? Does it

[103] A classroom where practical learning and demonstration take place in science, language, and other subjects

help to try new ways for communicating, supporting the development of all levels of the personality?

The two levels ("to do" and "to be") should grow together but it never happens because the western perception of the individual is still fractured. An example of this consideration is that the use of the body is still very unusual in the educational context.

At the basis of any educational process there should be the unconditioned trust in the potential of the individual. In traditional rehabilitation there is instead the need to comply with a performance standard. In particular the person with aphasia who lives a negative sense of self, reduced social activity and psychological morbidity, should be supported in the her/his need to communicate beyond stereotypes and outside the therapeutic settings where the person is considered someone who must become the same person he/she used to be before aphasia.

In my opinion there are much more effective educational experiences which consider transformation from a reality that does not exist anymore (the old self) towards a new identity to be re-negotiated. In particular, since traditional education is no

more suitable to the transformation of roles, demanded by society, which is particularly true for people with aphasia, we have to consider a new, non traditional pedagogy such as theatre lab that demands constructivist pedagogy, built upon questions, discourse, reflection, and transformative action.

But what do we learn when we engage in the arts? For example when we are working inside a real drama context? Debra McLachlan, during an annual course asked her senior students what they felt they were learning. At first, they talked about what they had learned about creating a play, producing, and then performing it. Soon, however, they began to talk about other things like: tolerance; self-direction; focus; self-discipline; the ability not only to generate ideas but to combine them with other people ideas; the ability to consider numerous possibilities without premature self-censure; and the pleasure in taking risks by experimenting and exploring. I have personally verified the same results in a theatre lab for people with aphasia, organized by my association but above all I had the privilege to follow the activities of Theatre Aphasique[104] group in Montreal, Canada. The following final reflections are

[104] Théâtre Aphasique is a Canadian non profit organization whose aim is to use drama for promotion of people with aphasia

the result of this experience and represent a first step towards the use of theatre in education for people with aphasia.

An ecological approach to education: the theatre lab

In the care setting, the body is seen as an abstract and purified body. Body and mind processes are inextricably linked, but the fact that her/his patient's body is immobilized, bridled, unable to express the language resources and potentiality, seems marginal for a speech therapist using a traditional approach. Body language is taken into consideration only as expression of "symptoms", confirming the idea of a separation between thought and body, perception and action, verbal and non verbal communication.

In aphasia therapy it is important to avoid the temptation of simplification and to switch from a speculative and abstract knowledge model to one characterized by the participated adherence to the context. We have to go beyond the separation between theory and practice towards an integrated concept of "theory as action". Our body connects with others; to make a

body alive within relations we need to observe it and to allow it to act.

Traditional therapy tends to emphasize the role of verbal communication, but applying Focault's educational theories to the rehabilitation context, we find out that the focus of education is neither the teacher nor the educational action, neither the methods nor the communication. The most important element of education is the network which connects all aspects and includes the care of space, time and bodies.

It can sound even offensive for people who struggle to re-gain the use of words, to highlight the limits of verbal communication in the rehabilitation context and to state that it should be able to open to the semantic ambiguity of body language. However what happened in the last 6o year in Italy was even worse. Communication was deprived of its physical roots and the words became empty like labels.

What is left when we exclude words? It is the body of the actor and his movements and actions. A body which can be re discovered through theatre which is not made of dialogues but of actions and addresses to senses rather than spirit.

It is not easy for a traditional trainer; you have to trust action, the only means to express the inexpressible, the deep and the essential beyond surface and appearance.

According to Mejerchol'd "to reconstruct the ability to communicate through the trained words in the session is like constructing on sand: it will collapse".

Personally I prefer the Theatre Labs inspired by Stanislavskij and Physical Action Method which focuses on the action which is not a synonymous of movement: "we have to use physical tasks because body is more solid than feeling".

What creates difficulties is the enormous unawareness of teachers and speech therapists of their own body, their whole organism, from and aesthetic point of view.

We must re discover the relationship with our body and with ourselves, through research rather than therapy, working on non verbal dimension in order to harmonize words and body. We must re-discover the patient as a three dimensional entity, focusing on body education.

In theatre Labs, the actor is brought back to the original condition of expression authenticity, depriving him of the text to stimulate him to use body language.

It would be a very useful method for people with aphasia according to the progressive-evolutive project consisting in going back to the origins, stimulating the individual to go through the ontogenetic and filogenetic evolution of human being, from physical silent (language d'action of Condillac)

possibly integrated by screams and unarticulated high sounds, achieving progressively verbal language.

In this case body expression would be a means, a tool used to achieve a goal. Communicating is a physical beside than intellectual activity. We have to work on the body and on the psychophysical sensations, focusing on the coordination body/thought (kinesthetic sense) process which is revealed by the muscular movements and can be improved through physical actions.

We will work on the kinesthetic sense and on the processes through which we subconsciously adjust the movements of our bodies, both as a response to external input and as response to the intentions we have in mind. We will observe the modalities used to carry out physical tasks, the processes through which people receive information about the external world and react to them without thinking it over and the reactions to information sent from the body to the brain.

Finally we will reflect on the fact that hemi paresis[105] effects the normal functioning of kinesthetic sense and the ability to successfully orientate one's body inside the space and in relation to other people or objects. In this case the coordination body/mind is disturbed. Our aim consists in developing

[105] People can, after a stroke, find it difficult to move their right arm or leg. (hemi paresis)

kinesthetic sense, training the individual like it was an actor to the use of the five senses, plus the kinesthetic sense. We must not forget that all our reactions are the result of sensorial experience; we all react to the presence of real object: if we see a lion behind us, we react; if we hear the sound of a train we keep away from the railway; if we do not hear an explosion, we are not taken aback. Without functioning senses there is no reaction and there is no life.

"To serve the basic learning needs of all requires more than a recommitment to basic education as it now exists. What is needed is an "expanded vision" that surpasses [...] conventional delivery systems while building on the best in current practices"

World Declaration on Education for All [Article2]
UNESCO, 1990

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