

# Stigma associated with hearing loss in older adults with hearing loss

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# Acknowledgements

## **Collaborators**

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## **Funding:**

'Hear-The-World' foundation (Phonak International) to Gagné and Jennings (2009)

## **Research project:**

*Stigma and disclosing (or not) one's hearing loss in the workplace: The strategies used by people with hearing loss*

# Dedication

Our work in the area of stigma and hearing loss is very much inspired by the earlier work of our colleagues at the University of Montreal:

Dr. Raymond Hétu (deceased, 1995)

Ms. Louise Getty

Hétu, R. (1996). The stigma attached to hearing impairment. *Scandinavian Audiology*, 25 (Suppl. 43), 12-24.

# Goal of Presentation

Describe the phenomenon of stigma and self-stigma related to hearing loss

Emphasize the importance of the stigma attached to hearing-impairment:

As a barrier to audiological rehabilitation (AR)

To propose avenues of rehabilitation that will make it possible to overcome the negative effects of the stigma associated with hearing loss

# Stigma and Hearing Loss

Negative stereotypes and prejudices are attributed to people who have hearing loss.

They are perceived as:

- old
- cognitively diminished
- Poor/uninteresting communication partners

Kochkin (2000) noted that hearing loss is often misunderstood as an intellectual challenge or a deficiency in personality and character

# Stigma and Hearing Loss

Markettrak Studies (Kochkin: 2000, 2007) indicate:

- Stigma is one of the main reason given by people to explain why they do not accept wearing hearing aids
- 40% of people with hearing loss who do not use hearing aids give stigma as one of the 5 main reasons for their decision

# Marketrak Studies (Kochkin, 2000, 2007)

Reasons given by adults with hearing loss who were between 35 – 65 years of age, to justify non-adoption of hearing aids:

Do not admit hearing loss in public – 35%

Noticeable – 35%

Too embarrassed to wear – 34%

Makes you look disabled – 31%

Makes you look old – 31%

A glimpse of the image that people with hearing loss have of themselves (their own identity)

# Stigma and Hearing Loss

Further reasons given by people with hearing loss to justify non-adoption of hearing aids (Kochkin, 2000, 2007):

Too proud to wear – 29%

People treat you differently – 28%

Makes you look weak and feeble – 26%

People make fun of you – 22%

Makes you look mentally slow - 20%



# Stigma and Self-stigma

**A conceptual framework for understanding the effects and manifestations of self-stigma associated with hearing loss**

# What is Stigma?

It comes from Greek:

Originally, individuals who were stigmatized were people who had a physical trait or characteristic that was considered 'deviant' or 'abnormal' relative to a reference group (i.e., the *outsider* group) in a given society

Devalued as individuals

They were discredited members of their society

# What is Stigma ?

Stigma is:

A difference

A discredited attribute\*

A sign of deviance from normality

Probably each one of us has felt discredited at a given time or in a given situation

It is likely that we have all experienced the effects of being stigmatized

\*you do not have to be a child molester to be stigmatized...to feel stigmatized

# Definition of Stigma

***Stigma is the possession of, or belief that one possesses, some attribute or characteristic that conveys a social identity that is devalued in a particular social context***

Crocker, Major, & Steele, 1998

# Stigma: A Social Construction

A label attached by society; a phenomenon defined by society

‘society’ is defined from a sociological perspective, meaning: ‘a group of persons regarded as forming a single community’ or ‘any organized group of people joined together because of some interest in common’

- Personal attributes that are stigmatizing in one society may not be stigmatizing in another society (e.g., tattoos; body piercing)
- Stigmatizing traits may change as a function of many factors including time (e.g., use of tobacco, homosexuality)

# Stigma: A Social Construction

Stigma is a social phenomenon that can be investigated from many different perspectives

- outsiders
- insiders

# Stigma: Perspective of *OUTSIDERS*

Stigma may be studied from the vantage point of people who do not possess the stigmatizing trait (members of society in general)

These people are '*outsiders*':

They are the people who hold prejudicial views; who stigmatize others

*Outsiders* report that people with hearing loss are old, senile, and socially unfit

Many *outsiders* avoid and/or ostracize individuals with stigmatizing conditions

# Stigma: Perspective of *INSIDERS*

Stigma can be studied from the vantage point of those who possess a stigmatizing trait

Those people are '*insiders*'

Usually *insiders* are aware of the prejudicial views held by the outsiders

Often, *insiders* hold (consciously or not) the same prejudicial views about their stigmatizing condition as the outsiders

In the case of late-onset hearing impairment, *outsiders* become part of the *insider* group



# Self-Stigma

Some *insiders* display *self-stigma*; these people agree with prejudicial views about their own stigmatizing trait

*Self-stigma* brings about a *threat to one's own identity (the way we perceive ourselves)*

*Self-stigma* often leads to higher levels of stress, shame, and lower self-esteem and self-efficacy

# Self-Stigma and maladaptive behaviors

To avoid situations of perceived identity threat, many people employ *maladaptive coping strategies*:

*denial* (possible because HL is invisible)

*minimization*

*normalization*

*social isolation/withdrawal, avoidance,  
concealing the loss*

# Maladaptive Coping Strategies

## **Denial**

The person insists that he/she is perfectly normal; that he/she does not have any problem hearing.

‘I hear very well; everyone mumbles these days.’

# Maladaptive Coping Strategies

## **Minimizing the impact:**

‘It’s not that bad!’

‘It doesn’t bother me!’

‘It does not stop me from living my life!’

‘I have some difficulties but I am not deaf!’

# Maladaptive Coping Strategies

## **Normalization attempts:**

‘It is normal when you have worked in noisy environments for 15 years!’

‘It is normal at my age!’

‘I am not worse than the others.’

# Maladaptive Coping Strategies

## **Withdrawal/Isolation:**

The person stops participating in social activities

The person prefers to stay alone, isolate himself/herself

# Maladaptive Coping Strategies

## **Concealing:**

Strategy used by some people who display self-stigma

Do not want to be identified as having the stigmatizing trait

# Maladaptive Coping Strategies

## **Concealing:**

Prevents individual from using appropriate communication strategies

Significant cognitive and emotional resources are expended in attempts to conceal hearing loss and the effects of hearing loss

Induces stress

when (and to whom) to disclose vs. when (and to whom) to conceal

Self-stigma is an important obstacle to AR



# Maladaptive Coping Strategies

To avoid being identified as a member of a stigmatized group, individuals might choose not to seek treatment or fail to comply with treatment regimens

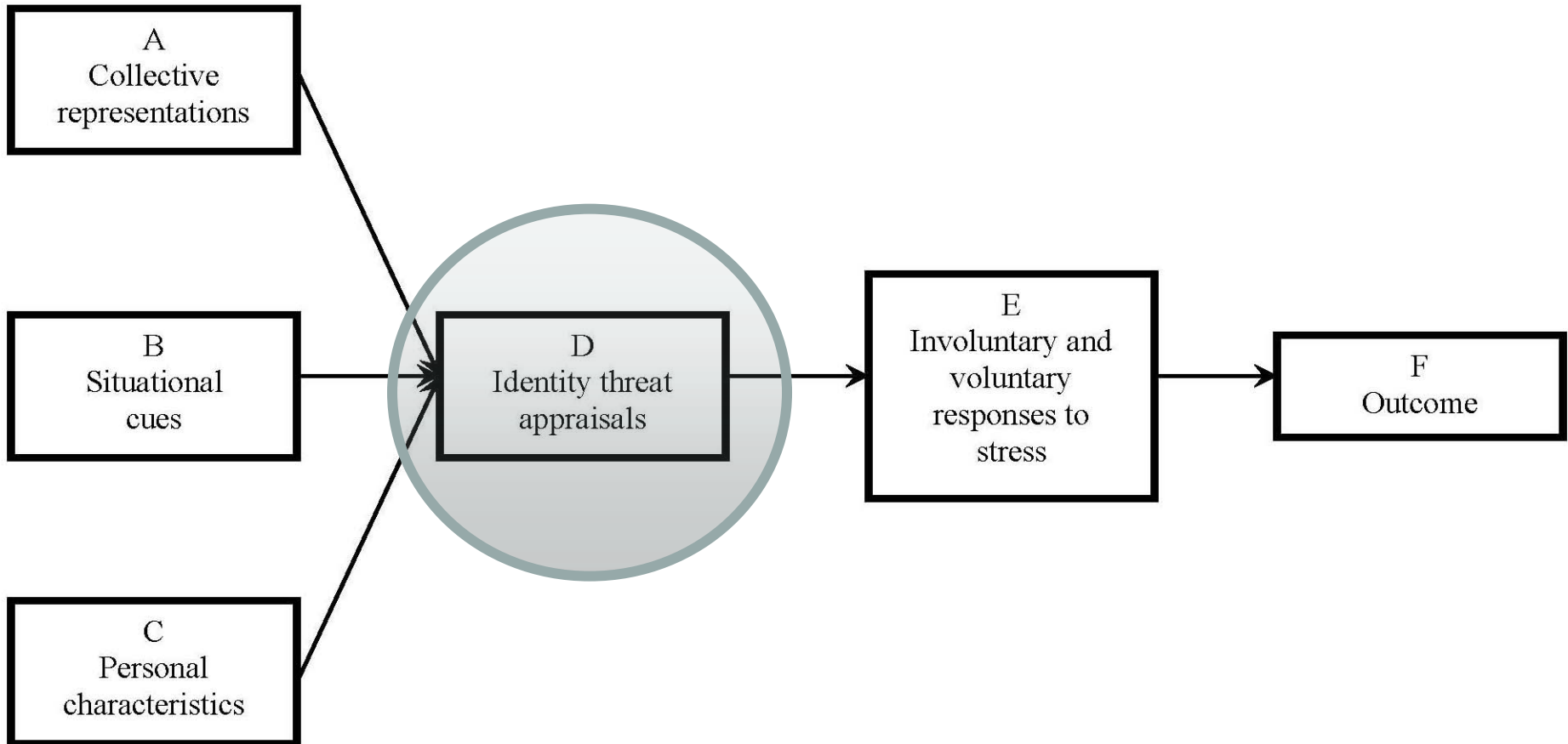
It is very likely that they will not agree to use amplification or any other type of assistive technology

# A Stigma-Induced Identity Threat Model

Major & O'Brien, 2005

Figure 3:

Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

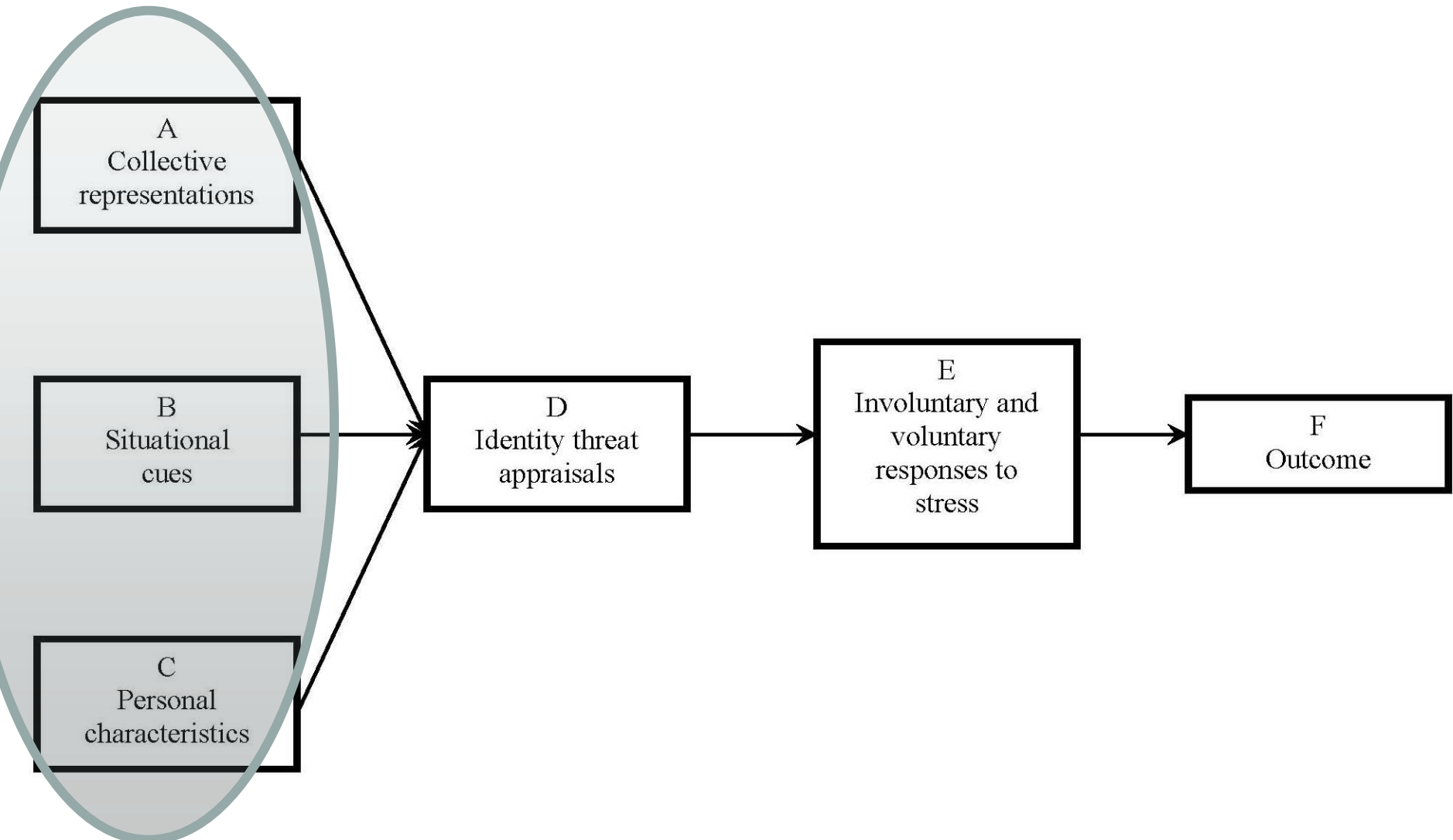
Responses to stigmatization depend on the person's assessment of the demands of the situation

A situation is assessed as stigmatizing if:

- one appraises a situation as harmful (or potentially harmful) to his/her social identity and
- when the stress induced by the situation is judged to exceed the resources available to cope

Figure 3:

Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

Appraisals of one's identity threat are determined by an interaction of the three constructs:

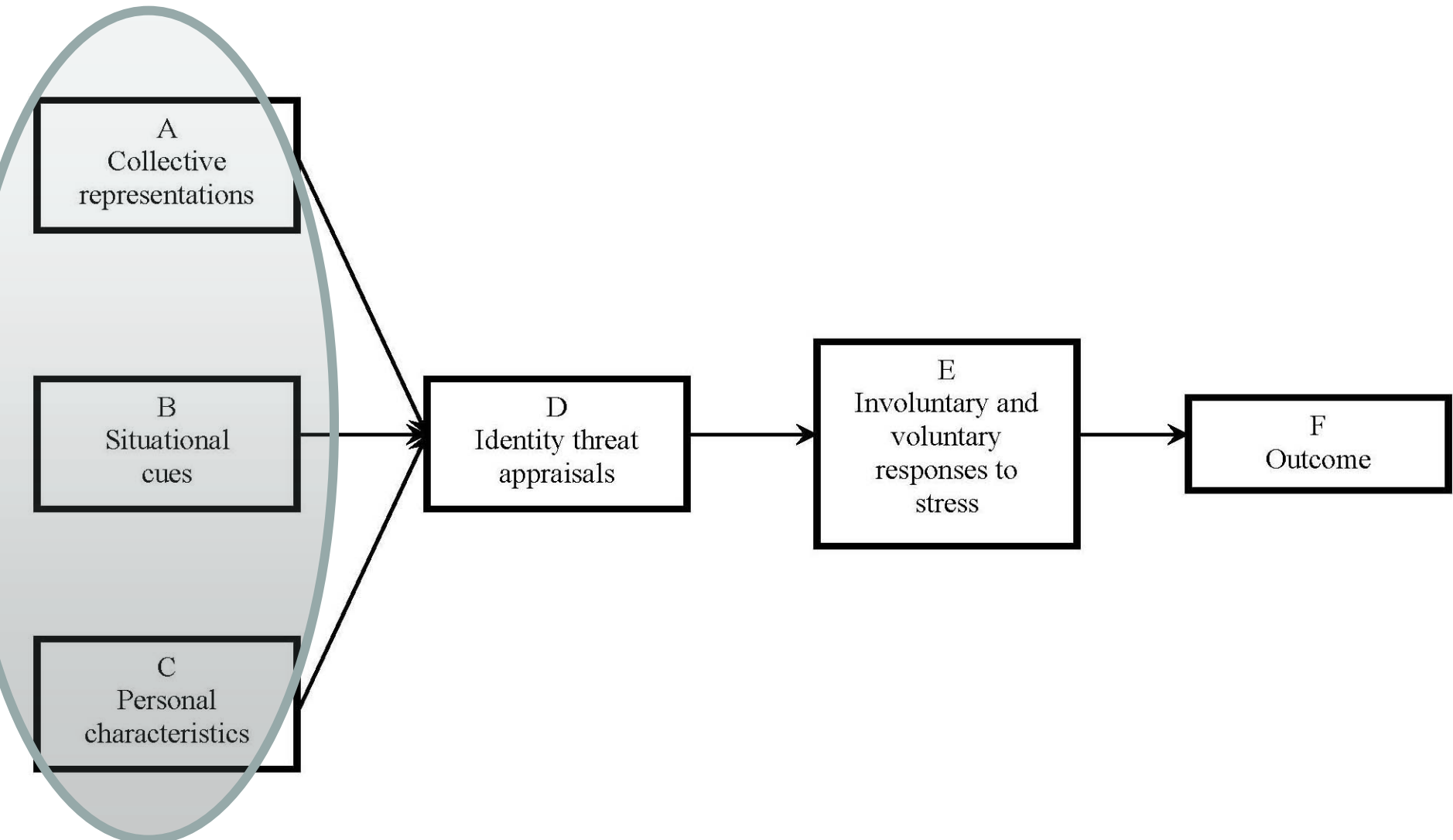
## 1. *Collective Representations*

Shared understandings and beliefs about stigmatizing conditions

Collective representations (society's) and the stigmatized person's own view of the stigmatized trait will determine whether or not their will be *a perceived identity threat*

Figure 3:

Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

Appraisals of one's identity threat are determined by an interaction of the three constructs:

## *2. Situational cues*

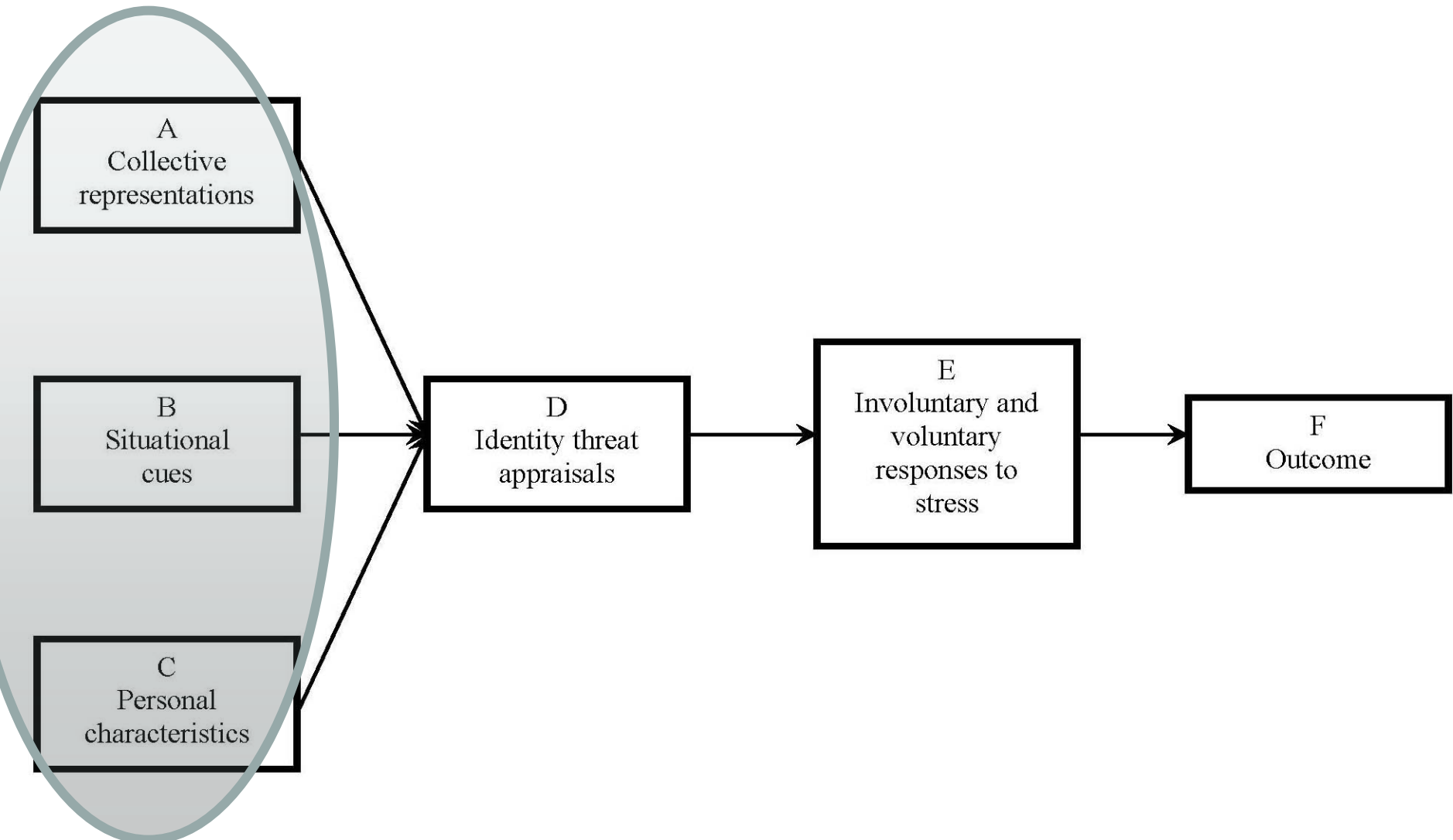
Factors related to the physical and social environment in which a given activity takes place

It is the person's perception of the situational cues that are important (real or not)



Figure 3:

Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

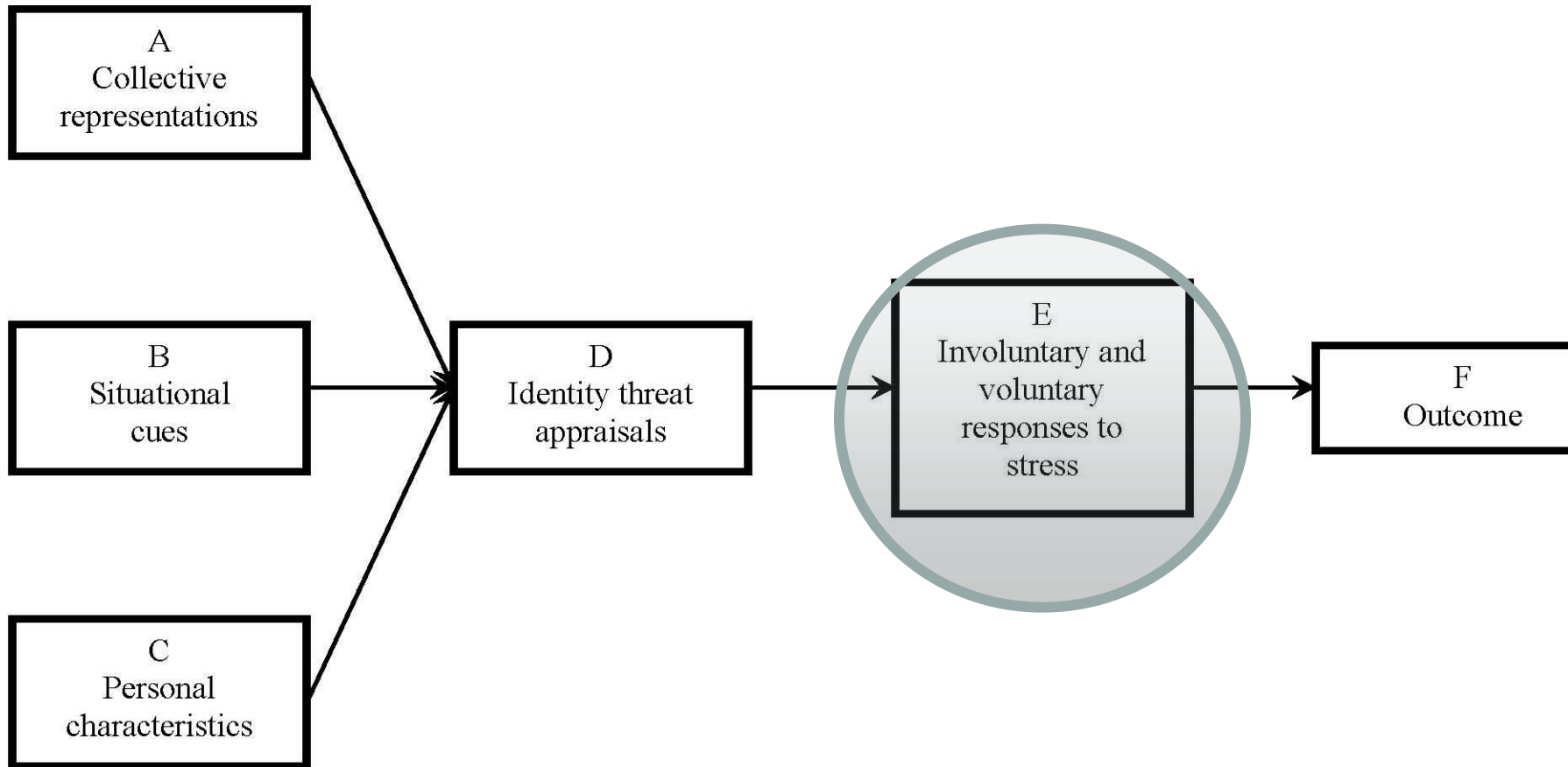
Appraisals of one's identity threat are determined by an interaction of the three constructs:

## *3. Personal Characteristics*

The personal attributes of the person such as age, gender, educational level, occupation, etc...

Attitudes, beliefs, level of optimism

Figure 3:  
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

Responses to stigmatization may be similar to responses that may occur in any stressful situation

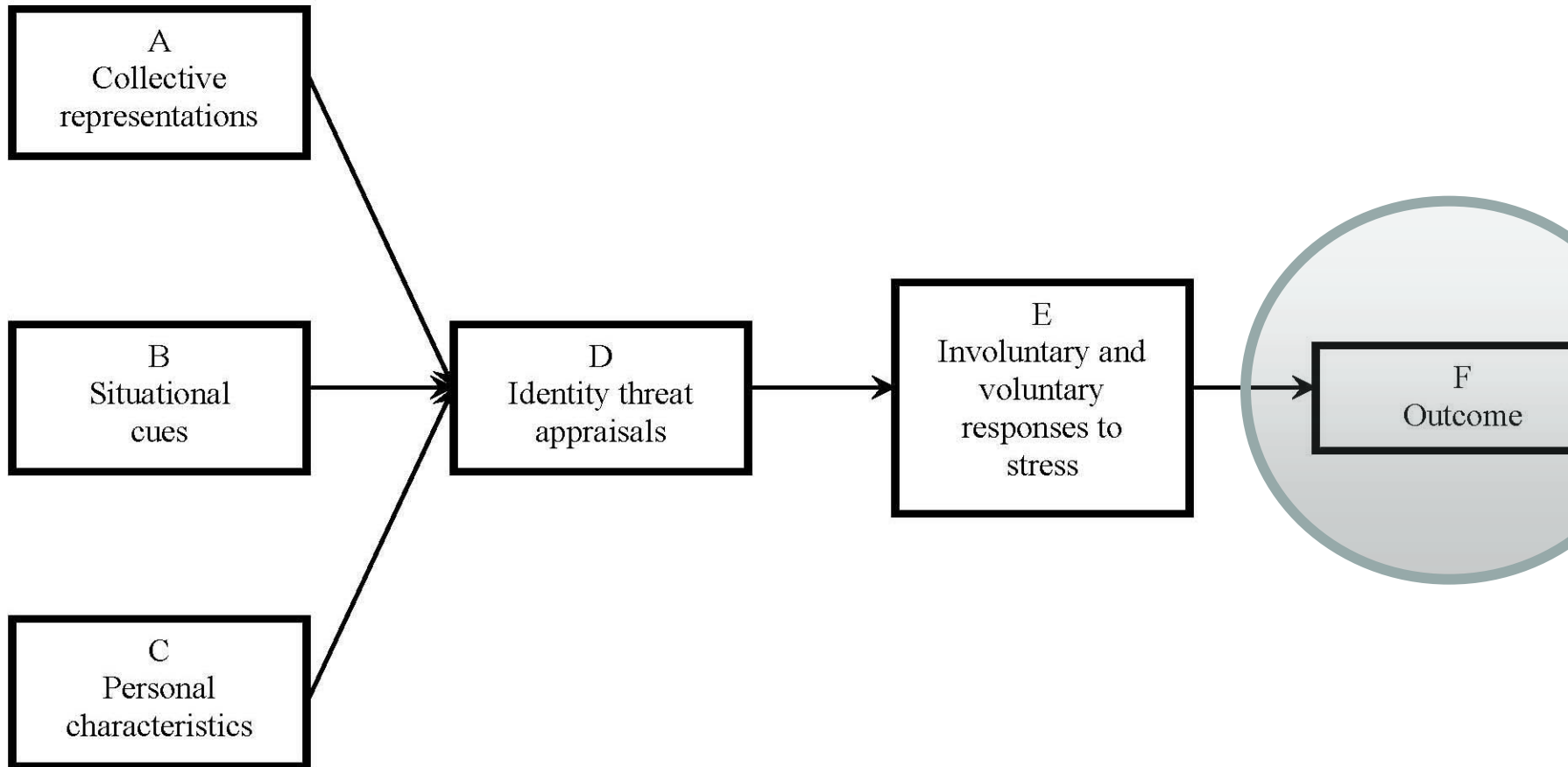
Responses to identity threat can be:  
involuntary (e.g., emotional, physiologic)  
voluntary (e.g., behavioral, emotional)

# Stigma-Induced Identity Threat

Coping strategies used to deal with stress caused by an identity threat are the same as the coping strategies one uses in response to any other stressful event

Generic models of stress and coping may explain how individuals react when they perceive an identity threat due to a stigmatizing event

Figure 3:  
Conceptual framework displaying the elements of the Stigma-induced identity threat described by Major and O'Brien (2005)



# Stigma-Induced Identity Threat

The outcomes of coping responses may be:

Attitudes (self-defeating, pessimistic)

Feelings (self-esteem, shame, fear, no confidence)

Behaviours (academic performance, job performance, isolation, health conditions)

# Implications for and Application to AR

Types of intervention programs:

Interaction with others who have the same stigmatizing trait (*Normalization Process*)

Cognitive-Behavioural Therapy, Social Learning Theory & Perceived Self-efficacy



# **The Normalization Process**

**Hétu, 1996**

# The Process of Normalization

Group Communication intervention programs:

Shares his/her life habits & experiences with others

Develops communication strategies

Shares its successes & failures with people living similar difficulties

Develops an identity (a sense of belonging) to the group

Reduces shame and deviance (normalization)

Develops a new social identity

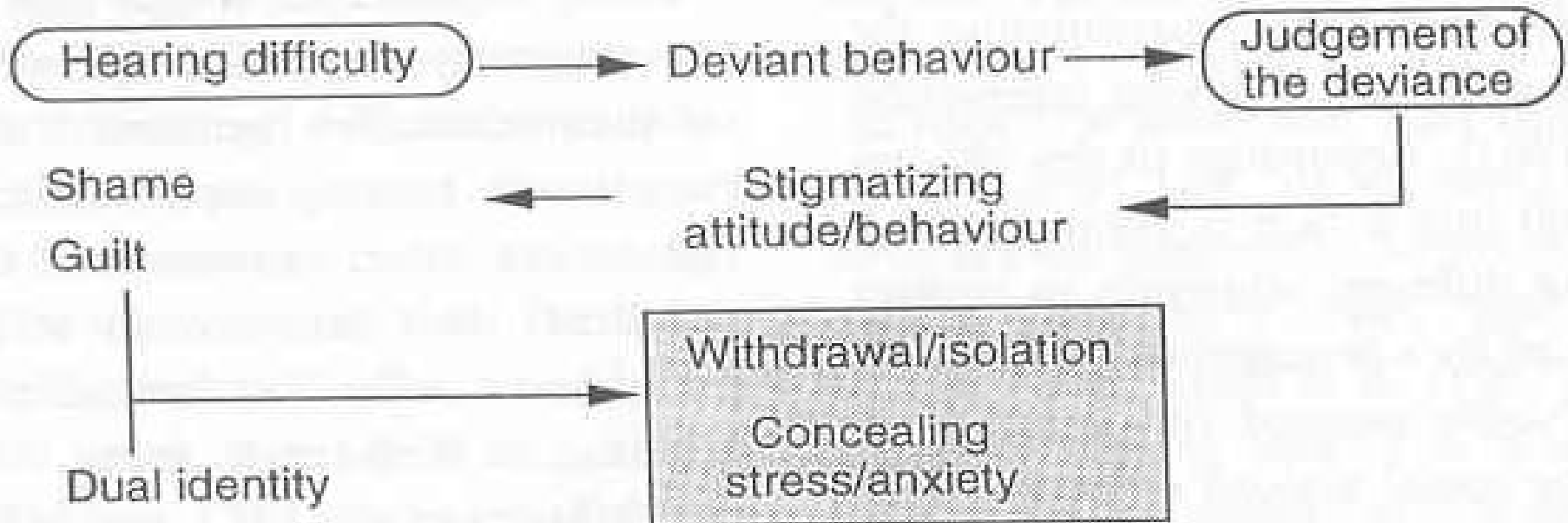
Restores a positive self-image

# Process of Stigmatization (Hétu, 1996)

## Stigmatization Process

Hearing-impaired person

Unimpaired entourage



# Process of Normalization (Hétu, 1996)

## Normalisation Process - Step I

Hearing-impaired person

Hearing-impaired peers

Hearing difficulty

Normal behaviour

Hearing difficulty

Support

Ridding oneself of guilt

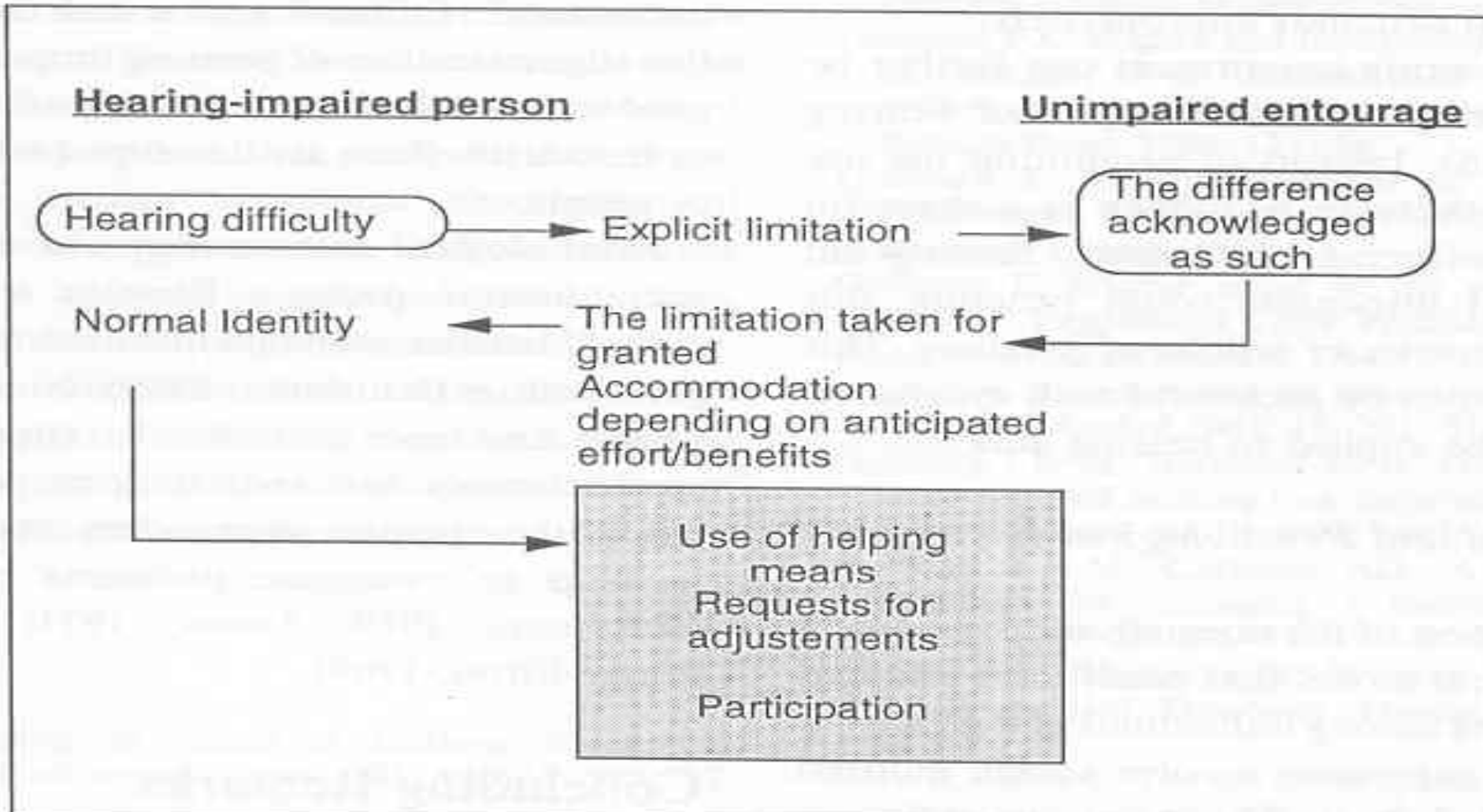
Sharing the difficulties

Normal Identity

Participation  
Sense of  
partnership

# Process of Normalization (Hétu, 1996)

## Normalisation Process - Step II



# The Process of Normalization

‘I am not the only person going through difficult, stressful, uncomfortable and shameful moments due to my HL.’

‘I am not crazy. It’s normal to feel and behave that way when one has a HL’

‘People with hearing loss are not necessarily old, uninteresting, unpleasant, etc... They just have difficulty understanding others in certain situations

# The Process of Normalization

‘Despite my hearing loss, I too can be a normal and interesting person.’

‘Strategies exist to reduce the number of communication breakdowns.’

‘I can simply inform my communication partners that I have difficulty hearing and that it would be useful for me if they used communication strategies.’

# The Process of Normalization

When the person's self-image is restored, they are more receptive to intervention. They will:

- More easily accept using communication strategies
- More easily accept wearing hearing aids
- Have more positive experiences and successful communication; increase their self-confidence; be less likely to adopt aggressive behaviours or withdrawal

And

People around them will be more interested in communicating with them, which improves the self-image (a positive 'vicious circle')



# Frameworks for Intervention

Cognitive-Behavioural Therapy  
Social Learning Theory  
Perceived Self-efficacy

# Using a Perceived Self-efficacy Framework

Bandura, 1977; 1986; 1995

Jennings, 2005

Jennings & Gagné, 2008-09

# PSE

PSE refers to, “beliefs in one’s capabilities to organize and execute the courses of action required to manage prospective situations.

Efficacy beliefs influence how people think, feel, motivate themselves, and act.” (Bandura, 1995, p. 2)

Outcome Expectations refers to,

“beliefs that performing the behavior will result in the desired health outcome.” (Ireland & Arthur, 2006)

# PSE

Major assumption, “unless people believe they can produce desired effects by their actions, they have little incentive to act.” (Bandura, 1998, p. 624)

To be competent, the individual requires both skills and SE beliefs to use the skills they have effectively

# Processes that Regulate Human Functioning

Bandura, 1997

## Cognitive Processes

Individual must believe they have the skills needed to act

## Motivational Processes

Individual must be motivated to act

## Affective Processes

Individual must believe that they are in control and are not vulnerable

## Selection Processes

Individual must have the ability and believe that they can problem-solve, plan, and be adaptive

# Summary

Self-Stigma is a barrier to AR

Understanding Stigma and Self-Stigma can assist us to develop AR programs to overcome the negative effects of the stigma associated with hearing loss:

Interaction with others who have the same stigmatizing trait (*Normalisation Process*) (Hétu, 1996)

Cognitive-Behavioural Therapy, Social Learning Theory & Perceived Self-efficacy (Jennings, 2005; Gagne, Southall, & Jennings, 2009)

Questions ...

Thank You!

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