



Working with Shame, Guilt & Grief: De-Stigmatising Disabilities in Ethnic Families

Presented by Dr. Maurizio Andolfi, 22nd May 2008

Notes from Session – compiled by ADEC

Note: Whilst these notes attempt to provide an accurate overview of the presentation given by Dr. Andolfi they are not a transcript and are therefore subject to the interpretation of the note-takers at the session.

In the past (prior to the 20th century):

- Psychiatric hospitals were always outside of town and people with mental disorders were hidden from the public. There was a belief that people with mental illness were dealing with a curse rather than an illness.
- We have come a long way from there but there is still a way to go

Migration in Italy:

- Italy has a long history of emigration – 25 million people have emigrated from Italy.
- Now that it has become wealthier, Italy is trying to encourage immigration.
- Many people in Italy are fearful of migrants and hostile towards them – fear of the unknown

Effect of the process of migration on people:

Grief

- Process of migration has a very significant impact on families
- It always involves leaving something behind – sense of loss
- It also involves the separation of families (particularly extended families) and this cut off from family can be like losing a limb.
- Because of this, migration can result in feelings of loss and grief.
- Often people will begin to idealise what they left behind and imagine life was much better back home than it actually was. They may forget or downplay the awful things that may have happened or caused them to leave.

Loss of power

- Migration also involves a loss of power – particularly when a different language is spoken in the new country.
- Language is not just a communication tool but also about power

Sense of belonging

- People always have a connection with the place they were born, even if they left when very young. There is a sense of proudness which is often very strong.
- This may create ambivalence in integrating into new culture.
- When people migrate they lose that sense of belonging and familiarity with their environment
- There is almost always different values and traditions which are unfamiliar and sometimes these conflict with the person's own values
- Belonging is closely related to a person's sense of self so a loss of this often effects a person's self-esteem
- This is not overcome simply by learning the language because even if you learn the language there can still be many misunderstandings.
- All this can result in a lack of confidence which may last for a long time after migration even when the person appears successful

It is important to understand these effects of migration when working with families from CALD backgrounds.

Disability

- Disability is often seen as a weakness and there is a sense of shame that accompanies this
- This sense of shame extends to the whole family as often the whole family becomes separated from the community and is not accepted
- Sense of shame can result in the family hiding the disability
- When a child is born with a disability there are often strong feelings of guilt for both parents, particularly when it is a genetic defect.
- There may also be conflict between parents because often a mother's capacity to deal with emotional stress is greater than the father's
- There is also a difference between being born with a disability and acquiring it – greater sense of loss because the person/family is losing their previous lifestyle
- Siblings are also strongly affected because often a lot of attention is placed on the child with the disability and the whole world can begin to revolve around them
- Often families become narrower and narrower. Extended families and friends may lose touch leaving the family alone
- There is a difference between sudden loss and grief felt after a death in the family. Often in this case people disengage from the community for a period but with time begin to recover and reconnect.
- When there is a disability in the family this doesn't happen in the same way

What do we do about this situation?

Look for strengths

- Need to look for strengths, resources and support within the family
- Move from feeling guilt and shame to feeling proud and strong
- Do this by focusing on the strengths within the family and within the person with a disability
- In Italy they still use the word 'handicap'. Some people have come up with a new term that translates as "otherwise able" – whilst this sounds strange it moves the focus from what the person is missing onto their other abilities
- Focusing on strengths is particularly important because often people who lose one ability compensate by developing other abilities very well (i.e: vision impaired people with a heightened sense of hearing)
- It is important to realize that the whole person is not disabled, just part of the person

Importance of family and community

- Look at the family as more than just two generations. Also extended family including grandparents, aunts, uncles etc.
- Community and social support is critical
- Keeping problems hidden from extended family and community inhibits recovery
- Often separation and segregation is the result of fear of the unknown & fear of something we don't understand.
- Sometimes it seems as if the more professional support there is for people within a society, the less the community is involved. For example in developing countries often there is stronger community support even though professional services are limited
- Maybe what we need is to increase community support rather than services
- Maintaining a sense of humour is also critical. It seems to be when someone is sick or disabled everyone needs to be sad and serious. Having a sense of humour will not make them any more disabled.

Importance of relationships

- One of the most important things for people is to have meaningful relationships
- No one is alone in the world – it's just a matter of taking the time to help a person find the right people to be around
- Often relationships and social interaction can have a more important effect on a person than medication – placebo affect

Challenging the medical model

- We need to challenge the medical model because it focuses on treating disease rather than people with disease
- Professionals need to explain things in simple language and take the time to make sure the family understands – need to connect people to the descriptions we give them
- Sometimes using metaphors is an effective way of doing this
- Psychiatrists need to be interested and curious about the person as a person – therapy is not based on drugs but on relationships
- Psychiatrists and doctors need to really engage with clients. Doctors struggle with this because they are not trained in dealing with the human side of illness and disability (the sorrow, grief, guilt).
- Also need to expand doctor-client relationships to not be one-on-one but involve the whole family
- It is interesting to note that there are no psychiatrists in the audience today even though they are often the people with the power when treating someone.
- Psychiatrists need to become more human and treat the person not the illness

Practical strategies

- In Italy they have tried a model where a group of people with disabilities live together in a house and are supported by each of their families. The families still support the household but the people can live independently
- Using creative outlets like music, painting and writing is very therapeutic and can also help people with disabilities connect with the community – i.e. put on an exhibition of artwork in a public space
- Need to acknowledge people's capacity to determine their own recovery programs

Family support groups

- Put together groups of people/families that can discuss disability (support groups) so people can share experiences and not feel alone
- This is very simple and powerful and helps to create community support

Cultural mediators

- This is a concept used in Italy whereby people who have migrated to Italy become trained as cultural mediators. These people are:
 - o well educated
 - o are fluent in the dominant language (in this case Italian) and understand Italian culture
 - o also speak the language of their home country
- They work to create a bridge between the migrant person and the wider community
- They are different to an interpreter because they do more than just interpret language
- Also listen and understand the needs of the family and discuss this with services involved – overcome misunderstandings
- They can help teach the family about their rights and responsibilities in their new home country and the traditions and values that are expected.