

Christine Bryden - Kyoto 2004

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My talk argues that people labeled with dementia should be given the choice for full participation in the local, national, and international Alzheimer's movement. It describes how the stereotype and myth of dementia have led to the stigma that prevents people labeled with dementia from participating fully in the life of the global Alzheimer's movement..

The stigma has created a barrier between people labelled with dementia, and the rest of society. This barrier is reinforced by the use of such terms as “mindless empty shell” to gain funds and support for the global Alzheimer’s movement.

As a person labelled with dementia, and as part of the self-advocacy group DASNI, I believe that it is unethical to collect and distribute funds on behalf of disabled people, without regard for our dignity.

Why should people labeled with dementia, as consumers of Alzheimer's Association support and services, be excluded from full and equal participation? By becoming more visible, in all Alzheimer’s Association activities, with ADI as our ally, people labeled with dementia can begin to break down the barrier of stigma that denies us our humanity.

There should be nothing about us, without us, in the global Alzheimer's movement.

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In 2000, a group of people labelled with dementia got together over the Internet, to support each other in self-advocacy. We formed the Dementia Advocacy and Support Network International, DASNI.

Our logo is a winged turtle, holding a forget-me-not flower. The turtle represents our disability, our label of dementia. Its wings symbolise our desire to be set free from the stigma that prevents us from reaching our full potential. The flower is a potent reminder that we do not want to be forgotten.

DASNI approached ADI in mid 2001, seeking a greater awareness of the contribution that people labeled with dementia could make. Like people labeled with intellectual disability, we wanted to be included, valued and appreciated as individuals.

In this relay race towards eliminating stigma, and towards self determination, each one of us - locally, nationally, internationally - is carrying a baton of change. But unlike people labeled with intellectual disability, we are declining daily. Not all of us in DASNI who picked up the baton and began the race in 2000 are still running. Others have now joined the race. They too will one day drop out, as they decline, and become too tired to stay in the race.

Because we cannot maintain the momentum of this race towards change, DASNI has handed the relay baton of change to ADI.

It is vital that ADI becomes the ally of people with dementia, and runs with the baton of change to the finish line.

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Dementia means “out of one’s mind due to brain disease or injury”.(1) This label of dementia gives rise to a stereotype and myth which together create a wall of stigma between people with dementia and the rest of society.

A stereotype is a simplified and standardized conception of a particular group of people that is invested with special meaning. A myth is something imaginary or fictitious, and can be an unproved belief that is accepted uncritically.(2)

The stereotype of dementia is of someone in the later stages of the disease. The myth of dementia is that we are all alike, all mindless empty shells.

The stereotype and myth of dementia lead to a belief that we all can’t speak and that we all lack insight. We are no longer individuals with unique characteristics.

As people labeled with dementia, we are expected to conform to society's expectations of this stereotype and myth.

But most of us in DASNI do not conform to your expectations, so our activities are questioned as lacking in credibility, and as not being representative of our labeled group.

We are limited by the stereotype and myth of dementia.

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The stereotype and myth of dementia is a distorted perception that leads to stigma, which can be defined as “an undesirable social property ... that is assigned to people when they have an attribute that deviates negatively from societal norms.”

(3)

Once we are labeled with dementia, society no longer looks beyond our disability to see the person within. This stigmatizing aspect of our identity can overshadow other aspects of who we are. (4)

The stigma of dementia leads to our exclusion from full and equal participation in the organizations that provide us with services and support. I believe that it is unethical to exclude us, as consumers, without regard for our dignity and our individuality. And without our subjective experience of living with dementia, how can policies, programs and services be better designed to meet our needs?

We people labeled with dementia are individuals who are diverse in the nature and severity of our disability, because of our personality, our life history, the time since the onset of our disease, the type of our dementia, and our support and medication.

But what we all share is the experience of living with dementia.

And what we all share, as a labeled people, is the oppression of stigma that masks our potential to participate fully in designing and modifying the services and support that we need.

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Stigma is a disease of society, adding to our disability. As people labeled with dementia, we live within a complex web of social encounters that are tainted with stigma. (5)

Dementia is not simply a disease of the person, but is a disease of society, due to the stigma that has been created from the stereotype and myth.

It seems easier for those of us who are trapped within this web to conform to the stereotype and myth, to behave in accord with the label of dementia.

Society values competence, intelligence and independence, and our label - created by stereotype and myth - denies us these attributes. They are not expected of us, and not encouraged.

Labeling theory suggests that “deviant behavior is behavior that people so label”.

So people can become what is expected of the label attached to them by society. It

is also suggested that deviancy amplification can occur, where the greater the stigma, the more likely the deviant behavior. (6)

Perhaps stigma leads to challenging behavior in people labeled with dementia.

Our label devalues us, we behave accordingly, and you respond. It’s a re-iterative cycle of reinforcing our differences.

As labeled people, we are showing what I call “adaptive behavior”.

We are adapting to the web of stigma that entraps us, that oppresses us, and casts a veil across every aspect of our lives.

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The stigma of dementia creates a barrier between two worlds - that of people labeled with dementia, and that of the rest of society. “The two worlds are set apart socially by the stigma that is associated with [our] disabilities.” (7)

Behind this barrier of stigma, we labeled people experience loneliness.

We cannot meet the expectations of the world on the other side of the barrier.

How can we maintain friendships with you, if we are expected to remember your name, what you told us just now, or what is happening in your life?

You focus so much on our cognitive self, rather than trying to relate to the deeper emotional and spiritual self that each one of us shares and can connect with.

In the past, the system itself, the global Alzheimer's movement, has reinforced the barrier, by portraying us as mindless empty shells in its efforts to seek funds

We need to break down this barrier, to remove the stigma, by addressing the stereotype and myth of dementia that created it.

This means that we need to avoid such terms that imply all people with dementia are alike - they are all “demented”, they are all “sufferers”, they are all child-like, or all lacking in insight.

We need to focus on emotions and spirituality rather than cognition, as we begin to find out ways to communicate across the barrier that divides us.

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Our lack of visibility reinforces the barrier of stigma. Whilst we remain invisible, you will continue to believe that people labeled with dementia are all alike. We will remain trapped behind the barrier, our unique identity masked by the label of dementia.

An important way to address stigma is to include us in all of your activities, and to look beyond the stigma to our living reality. By becoming visible as individuals, we can be seen as people first, before our disability. We can also be given purpose and meaning in our lives.

People labeled with dementia want to have the choice to participate in the local, national and international Alzheimer's movement. Use us in your fund and awareness raising. Train us to work alongside you in lobbying governments, and appearing in the media. Let us help in the office doing whatever we can. Your staff will enjoy meeting us, and we will become a reality to them. Some of us can be passionate advocates for a cure, and for support and treatment.

By making us visible, you will be our ally in this struggle to remove the stigma of dementia. You can help us to maintain our identity despite the label of dementia. We can help you to improve services and support.

Help us to discuss issues with our peers, in a safe environment in which we are not judged for our competence. Listen, record, reflect back, capture, summarize, and reconstruct our views.

Believe in our potential, you need us and we need you.

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We need you to run the race towards eliminating stigma for us. DASNI has done, and will do, all it can. But each of us who is labeled with dementia is declining daily and cannot continue the battle against stigma for very long.

People labeled with intellectual disability have been able to cross the barrier of stigma into the world of “normals”, after a very long struggle with stigma of between 10 to 30 years. (8) But people labeled with dementia do not have this amount of time to battle stigma.

We could try other options, such as seeking the positives of our disability, or pretending to be normal by covering up. But the only viable option for people labeled with dementia, and for the global Alzheimer's movement, is to work together to eliminate the stigma of dementia. This will enable society to appreciate the humanity of each person labeled with dementia, at each stage of our increasing disability.

As a labeled people, we have the most to gain from eliminating stigma. We must be given the choice to participate in the battle to remove it. Few of us will have the desire or the fortitude to get involved, but we must be given the choice. (9) Self-determination is the key.

Until people labeled with dementia are engaged locally, nationally and internationally, the Alzheimer's movement cannot hear our voice, and cannot develop the services and support for us as consumers.

Be our ally, value us and give us our dignity and individuality.

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Become our loyal allies, and use people labeled with dementia as visible representatives in the shared cause of eliminating stigma.

Don't rely on the stereotype or myth to garner funds, rely on the real thing - the people who are labeled with dementia.

The stereotype and myth of dementia cannot be sustained when we become seen as individuals.

As we become more visible, as our subjective experience is explored, we will be able to influence our quality of life.

Together we can enhance the self worth of people labeled with dementia, as well as enhance the services and support provide through the global Alzheimer's movement.

Together we can challenge the stigma.

Let's stand together the spotlight and adopt the slogan "Nothing about us, without us!"