

ARE YOU LIVING AND AGING WITH A DEVELOPMENTAL DISABILITY?

BY MAUREEN ARCAND



ARE YOU LIVING AND AGING WITH A DEVELOPMENTAL DISABILITY?

By Maureen Arcand

October 2003

This paper was funded by the Wisconsin Council on Developmental Disabilities (WCDD) using federal funds provided under P.L. 106-402 through a grant authorized by the Administration on Developmental Disabilities and the U. S. Department of Health and Human Services. The information herein was compiled pursuant to the State Plan on Developmental Disabilities. Grantees undertaking projects under Council sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions expressed do not, therefore, necessarily represent the official position or policy of the Wisconsin Council on Developmental Disabilities.

Presentations and reports are based on research done through the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC), University of Illinois at Chicago which is funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Research (Grant No. H133B980046).

Wisconsin Council on Developmental Disabilities
600 Williamson Street, PO Box 7851, Madison, WI 53707-7851
608/266-7826 ? FAX 608/267-3906 ? TTY 608/266-6660
Email: *hfswiswcdd@dhfs.state.wi.us ? Internet: www.wcdd.org

Are You Living and Aging with a Developmental Disability?

By Maureen Arcand

I am a person with a Developmental Disability. My disability is from Cerebral Palsy (CP). I am over 70 years old. When I was in my 50's, what I could do changed. I couldn't walk as far and as fast, I fell more often, and I had pain in my neck from arthritis. When I went to the doctor, he said I was getting older. No one could tell me much, because before that, people with CP had died before they were 50 years old. I knew then that I would have to find the answers for myself, and that I would share those answers with other people with disabilities. That is what I'm doing now.

As people with Developmental Disabilities, including most forms of Mental Retardation (MR), Cerebral Palsy (CP), and Epilepsy, we have always known our disabilities would be part of our whole lives. If we are now over 50 years old, we didn't think we would live to be that old. We are pioneers, because we are the first people with these kinds of disabilities to live long enough to wonder about getting older. Now many of us are 50, 60, 70, and even older. Here are some things we need to know.

It is important to know that our disabilities make a difference in how we age. We are all different, so what happens to us will be different and may happen at different times. Knowing what to watch for can help us understand what is happening. What kind of disability we have makes a big difference. We know now that there are different kinds of Mental Retardation. Autism and Down Syndrome are two kinds, and there are other syndromes. If you have Down Syndrome,

you may begin to age in your 40's, but if you have another kind of MR you may be in your 50's before you feel changes in what you can do.

Some of us with Cerebral Palsy may begin to feel tired and not be able to do as much as before, when we are around 35 years old. Sometimes it is a good idea for us not to use all our energy to walk. Using a wheelchair to get around may mean we have more energy to do other things.

Living longer should be a good thing---something to be proud of. Not only are we living longer than people with DD ever did before, but we have had more chances to live in the community, to have jobs, to have friends, and do things we like to do. We can keep doing these things even when we get older. We should not be afraid of getting older. Knowing that we can get older should help us take better care of ourselves. It's important that we tell people close to us when we feel changes in how we feel and what we can do.

The answers on the next two pages should help you as you live the years ahead of you. I have put the information in simple terms to show you what might happen. Some of it is what I have learned myself and some is from what other people learned from talking to people with disabilities like ours. Use them to help you enjoy your life.

Facts About Aging for People with Developmental Disabilities

Compiled by Maureen Arcand

If you have Mental Retardation, Autism, Down Syndrome, Cerebral Palsy (CP), Epilepsy, or any combination of those, you have a Developmental Disability (DD). Throughout life, everyone gets older, and if they live long enough, they will experience the aging process. All people are living longer than they used to, and so are people with all kinds of disabilities. Living longer should be a good thing. People with DD have lived with our disabilities all our lives, and know that in some ways our lives have been different than other people's. For the first time, we have to ask if what happens to us when we get older will be different than what happens to other people.

RESEARCH

For about 15 years, people who cared about us have been studying these questions, and have found out some things which can help us.

They have found out that the changes that happen to all people when they are over 50 begin to happen to people with DD earlier---sometimes in their 40's. These changes often happen to people with Down Syndrome even earlier.

Here are some of those changes:

1. We get tired easier and quicker.
2. We don't see and hear as well.
3. Walking may be harder work.
4. We may lose our balance easier and fall.
5. We may have to go to the bathroom more often.
6. We may have more trouble remembering things and figuring things out.

For some of us, the changes begin in our 40's, which is earlier than for people without disabilities.

Here are some ways these changes may be different because our disabilities are different:

1. People with CP notice changes in all parts of the body which have been affected by the CP, such as walking, talking, breathing, swallowing, and bowel and bladder control.
2. Changes happen to people with Down Syndrome earlier.
3. People with CP may have Arthritis in their 30's.

Here are some ways we are like people without disabilities:

1. We are living longer than people ever have before.
2. People with DD can have the same health problems that happen to all older people, such as Heart Disease, Diabetes, and Arthritis.
3. Many people with mental retardation are overweight, especially women. This adds to their health problems.

What should we be doing to make our lives easier and healthier as we get older?

1. We should be exercising as much as we can. Walking, swimming, and exercise classes are all good ways.
2. We should eat food that is good for us, like fruits and vegetables instead of fast foods and sweets. This helps us lose weight.
3. We should take care of our teeth.
4. We should tell someone if we're feeling stressed out or sick.

IT IS IMPORTANT TO KNOW OUR OWN BODIES, SO THAT WE KNOW WHEN SOMETHING CHANGES.