

family

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Record

218

File Number

10193

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Title: Great expectations...Disability can inspire them

Original source: Families and Disability Newsletter Volume 2 Number 1

Resource type: Written

Publication Date: 01/01/90

Publisher info: Beach Center

Abstract

This short article describes the four qualities of "Great Expectations" - vision, hope, determination and revision. It shows how these great expectations create real benefits for communities and how they cause mixed emotions for families.

Keyword: Families

Great Expectations ... Disability can inspire them
excerpt from Families and Disability Newsletter
Vol.2 No.1

Have you ever wondered what "Great Expectations" means to families like yours, those with a son or daughter with a disability? What does it mean to have "Great Expectations": for your son or daughter with a disability? For your family? For professionals who often urge family members to "accept reality"? For each and every one of us in the community? We have wondered, and we have some ideas that we would like to share.

First, **Great Expectations are for everyone.** All of us have dreams, visions, and anticipations for the future. Most of us go out into the world, get feedback from it, and alter our dreams, visions, and anticipations. Like everyone else, people with disabilities and their families have Great Expectations; like everyone else, they too need help to be able to have their expectations come true. They need to believe in their own strengths, assume control over their sons or daughter's future, and anticipate a future with choices and fulfilment. But professionals and other people without disabilities also need to have Great Expectations for people with disabilities.

Second, **Great Expectations combine four qualities: visions, hope, determination, and revision.**

- *Visions* are the myriad possibilities that families, friends, associates, and people with disabilities see for themselves and for members of the community.

Visions are more than dreams, they focus on specifics. At a recent Family Leadership Conference in Washington, D.C., sponsored by the Office of Special Education and Rehabilitative Services within the Department of Education and convened by the Beach Centre, family members talked about their visions. A father told us this vision:

My son is 21 years old and profoundly deaf. I also have two foster children. He is a minor league baseball player for the New York Mets. He went to the College of William and Mary and has played soccer on the youth national team. My vision includes the dream that all hearing impaired children have the opportunity to benefit from what my child has done, and then to have my child play left field for the New York Mets.

What are your *visions* for yourself? For your child with a disability and your neighbours, colleagues, and other fellow citizens in your community? What can you do to nurture and develop your visions, and share them with others?

- *Hope* for the future gives rise to visions.

Hope is an essential part of Great Expectations. In the past, life-long institutionalisation was the only choice for many families. At the present time, some families have the choice of small group homes and sheltered workshops as the residences and workplaces for their sons and daughters. In the future, families will have other choices, including

supported employment and independent living. Another parent at the Family Leadership Conference voiced that hope:

My child has mental retardation and is 25 today. Indians lack services that are afforded others. He lives in a group home, and works in a sheltered workshop and loves it. The wage scale of the persons in sheltered workshops needs to be looked at. He gets 35 cents an hour, and other people with disabilities need to have their pay scale looked at. We need vocational schools to become trained in, and to help look at realistic opportunities for the future. Since he likes to hammer, my vision is for him to become a carpenter, and maybe for him to become a janitor since he likes to clean schools.

What are your *hopes* for yourself? For your family? For your community? What are you doing to make that hope a reality?

- *Determination* is a must to achieve Great Expectations.

It is hard to have hope for the future while living in the present or to be accepted for doing so. Achievements do not just happen; they take a lot of hard work. Another family member's comments reflect determination:

I have a son who is ten years old and has Down syndrome and related severe health problems. The few months he spent in the integrated setting facilitated such dramatic growth for my son in all developmental areas that our family has decided to maintain two separate households in order to regain an integrated program. My vision is to regain the glimpse of my son as he was in the integrated setting in terms of his self-esteem and developmental growth. A second vision is that the price of a split family and commuter marriage won't have to be endured by other families seeking appropriate educational programming in the least restrictive environment.

What are you *determined* to do for yourself? For your child with a disability? For others in the community?

- *Revisions* of Great Expectations are normal.

They come from feedback that the world gives us. There is a saying that "Experience makes good judgment. Mistakes make good experience." All of us make mistakes, but all of us also surprise ourselves and others by what we accomplish. We react in different ways to our experiences. Working with others - professionals, neighbours, co-workers, family, and friends - can change our expectations, strategies, and choices. Another parent comments on revisions:

Once, our son and we set our goal to be his social integration. It seemed to be a high goal. Later having reached it, we set our goal to be his living on his own, with non-disabled housemates. We have reached that. We all worked very hard to get where we are. We were called "unrealistic". But our work paid off. Now what's next? Volunteering at the church? Voting in the next elections? Where's the limit?

What kind of *revisions* have you made in your plans for yourself? For your child with a disability? For your life in the community?

Resources and services are the third aspect of Great Expectations - vision and dreams are not enough. Currently, it costs about \$53,000 annually to care for a person with disabilities who lives in an institution. Families who care for their child with disabilities

at home want and deserve a reallocation of resources from institutions to communities, services that combine professional support with more informal support, and movement from facility-based endeavours to community-integrated ones. Instead of urging families to "accept reality", professionals should help families expand reality to make their dreams and visions possibilities. One mother describes her vision of a need-based support system:

I don't come from a traditional family. We have three daughters, one son from Ethiopia, and a dependent mother. We are not asking for more than we need. We need a system to be productive. Also, giving the family what they need. When a family says they need help in getting laundry done, help them get the laundry done, don't give them counselling as to why they haven't been able to get the laundry done.

Great Expectations, with resources to help them occur, create real benefits for communities. Benefits to communities are real. Every person with a disability who has supported employment becomes a taxpayer. Persons with a disability who volunteer time to a community program give more than their time - they give of themselves. These particular achievements benefit the person with a disability, the family, and the community.

Fourth, **achievement and independence are not the cornerstones of Great Expectations.** Great Expectations include feeling control over one's life, a feeling of meaning in one's life, and a sense of one's own value. Research by Shelley Taylor provides a theoretical backbone for these concepts. But these feelings are universal, as one parent notes:

I am the parent of three sons. The youngest is deaf and chronically ill. My vision is no different from that of other parents. I want my child to be happy, productive, loved, in love, and accepted.

Finally, **Great Expectations entail mixed emotions from families.** Family members may be anxious or confused about the future; they may feel unsure. They may be disappointed when their Great Expectations do not materialise. Society's attitude towards people with disabilities can create mixed emotions. Brothers and sisters also experience the mixed emotions that accompany Great Expectations for people with a disability. As one sister comments:

I want my sister to be able to do all of the things that the other kids do. But sometimes I get mad when she plays with my tapes without asking me, and once at the grocery store she started yelling and I was embarrassed so I waited in the car. But some days I am proud of the way she works really hard. Like when she learned how to ride a bike. Now we can go on bike rides together.

Visions...Dreams...Great Expectations. The challenge faces all of us. The rewards are there for all of us. But only if all of us have Great Expectations for each other, especially for people with disabilities and their families. After all, Great Expectations are for everyone.