

7. Personality and Emotional Development

1. Just as a child without a disability will normally develop multiple “identities” (e.g. boy/girl, neighbour) they will almost certainly to some extent develop an identity as a “Person with a Disability” which, when combined with other personality characteristics, will have an impact on how others relate with, and respond to them.

These identities could include being known as a man, woman, sports fan/person, road user, university/TAFE student, member of the local community, etcetera.

The following is a small list of potential names, or labels that can be applied to anyone, regardless of whether or not they have a physical disability.

Troublemaker	Volunteer	Friend	Wife/Husband
“pain in the butt”	Student	Mate	Introvert/Extrovert
Sportsperson	Advocate	Partner	Parent
Nuisance	Civic Leader	Confidante	“Doormat”

As “Shaun” says in this quote a person’s disability status is only one part of their life and personality, and does not make any difference in some settings, like an internet discussion:

I think it’s only relevant [to disclose your disability,] when you need to establish your credibility to talk about a subject relating to disability. For example, people don’t need to know that I have a disability if I am contributing to an analysis of the last All Black test, fine wines and food, movies, raising teenagers etc because it has no relevance. What might be more relevant is my gender, age, race, socio-economic status, parental status, academic background, where I live, who I know etc etc etc.¹

Adjustment to life with a disability (regardless of whether the disability, is genetic, or “acquired”) is said to be a normal part of life with a disability. A writer/teacher with a spinal cord injury is reported in one piece of research as observing that;

I should have picked up the pieces and made the adjustment, and not dwell on it. The problem is that the rest of the world is dwelling on it. Every time you go out there, you’re reacting to all this ridiculous attitude problem, the architectural barriers, the financial discrimination, and this place won’t hire you and this company won’t insure you and that potential lover won’t look at you. . . . So that reopens the wound maybe twenty times a day and yet you’re supposed to have made the adjustment. You have to work through a lot of stuff in a continuing way.²

A blind writer quoted in the same research, says “The adjustment process is a lifetime project” (p.72).

¹ P. 335-336, Bowker, N., & Tuffin, K. (2002) Disability Discourses for Online Identities. *Disability and Society*, 17 (3) 327-344.

² P. 72, Noonan, B. M., Gallor, S. M., Hensler-McGinnis, N. F., Fassinger, R. E., Wang, S., & Goodman, J. (2004) *Challenge and Success: A Qualitative Study of the Career Development of Highly Achieving Women with Physical and Sensory Disabilities*. *Journal of Counseling Psychology*, 51 (1) p. 68-80.

1. Development of a sense of who they are, and their place in the world, are different for children and adolescents with a physical disability;

As noted in recent West Australian research³, the time of transition from school to post school options

...is potentially difficult in the life of any young person and his or her family... However for a person with a disability and his or her family, it throws into stark contrast the widening gap between the ways in which they might be forced to operate as a family and confirms for the parent their different and continuing role in the life of their child. From this perspective transition from high school, which may be seen as a rite of passage to adulthood for most families, is potentially the path to greater dependence for the target group of this study. (p.5)

A large American research project about women with physical disabilities⁴, noted three important factors that particularly affect the sense of self, of women with a physical disability.

These include; a.) Work, and the additional barriers and disincentives to enter the workforce, for women with a physical disability, and the resulting implications for financial independence, and positive self-esteem; b.) Relationships and the reduced opportunities to develop romantic relationships, again with implications for self-esteem, and; c.) Abuse, which appears to be related to the reduced opportunities for escape from less than ideal situations, due to factors related to dependence, environmental barriers, and social isolation.

The same research noted how those women they interviewed, who had a strong positive sense of self, had tended to;

- a. Appreciate their own value;
- b. Asserted their right to make choices that improve their lives;
- c. Felt ownership of their bodies;
- d. Avoided allowing their sense of sexual self be diminished by negative images associated with their disability;
- e. Were accepting, not ashamed of their bodies, and;
- f. Took action to enhance their attractiveness. (p. 11.)

One of the findings of the research, (that could be applied to men as well as women,) was the need for esteem building activities for those with physical disabilities.

³ Yates, C., (2002) Transition from School: Outcomes for Rural Families of School Leavers with Disabilities. Unpublished master's thesis, University of Western Australia, Perth Western Australia.

⁴ Nosek, M., Howland, C., Rintala, D., Young, M., & Chanpong, G., (2001) National Study of Women with Physical Disabilities: Final Report *Sexuality and Disability*, Vol. 19, No. 1, 2001

For example, participation in sporting and social activities, with peers, both with and without physical disabilities, will improve the self esteem and self worth of those with physical disabilities.

An Australian researcher⁵ writing about young people, notes previous research with 162 young people with either spina bifida or cerebral palsy, and how "...over-protection was found to be related to lower self esteem and self-worth...and these young people had very limited responsibility in the home and linked involvement in such activities to a measure of social worth within the family."

2. Development of skills and techniques to help cope with, and adjust to, the additional stresses and frustrations related to being a person with a physical disability are important in improving quality of life.

Stresses and frustrations related to having a chronic illness or disability include, threats to

- b) One's life and well-being;
- c) Body integrity;
- d) Independence and autonomy;
- e) Fulfilment of familial, social, and vocational roles;
- f) Future goals and plans;
- g) Economic stability.⁶

Various strategies have been identified for coping with disability. Coping is defined in some research as "...a *psychological strategy mobilized to decrease, modify, or diffuse the impact of stress-generating life events.*"⁷ Some ways are better than others, and identified in the same research. Basically they refer to two broad types.

Positive options include **Engagement coping strategies**: Efforts that defuse stressful situations via problem solving, seeking social support, planning and information seeking.

Less positive options come under the category of **Disengagement coping strategies**: These are things like dealing with stressful events through passive, indirect and even avoidance activities, like denial, blaming oneself and others, and substance abuse.

⁵ p. 44, Bricher, G., (2001) "If you wanted to know about it just ask": Exploring disabled young people's experiences of health and healthcare. Unpublished doctoral thesis, University of South Australia.

⁶ Livneh, H., & Antonak, R., (2005) Psychosocial Adaptation to Chronic Illness and Disability: A Primer for Counselors. *Journal of Counseling & Development*, 83 12-20.

104 Billings and Moos, 1981, Lazarus & Folkman, 1984, cited at p. 14, Livneh & Antonak (2005).

Recent Canadian research⁸ suggests the following as ways people with a physical disability have found to successfully deal with, or seek to reduce stress. They fit broadly into five categories;

Socializing social support: Mixing with family and friends. For example, two women noted how they found socializing with friends who looked beyond their disabilities as refreshing and promoting a sense of acceptance. As one participant said:

“I like going out and being around people that won't look at me and say, 'She has a disability.' Just being out and sort of maybe playing. It's kind of a nice relief when you can go out and nobody is making it an issue or it doesn't have to be an issue. (p. 23.)

Cultivating and using positive affirmations; basically, maintaining a positive attitude. As well as using techniques like self-talk, self-reflection, self-acceptance, and self-learning. For example, many professionally successful women with disabilities, turned negative experiences into an opportunity for personal and professional growth.

Raising a well adjusted teenager doesn't happen overnight, start early! In his book *Being a Happy Teenager*⁹, Andrew Matthews asks:

“Does Positive Thinking Help?

Imagine you are sitting in a jumbo somewhere over Europe, and an engine falls off the wing. How would you want the pilot to react? Would you want your captain saying: “Stay calm and buckle up! This will be bumpy but we'll find a way home?”

Or would you want your captain running up and down the aisle yelling: “We'll all be killed! We'll all be killed!”? Which fellow is more likely to get you down safely?

Now think about your everyday life in which you are your own pilot. Which approach is most likely to solve your problems: “We'll find a way”, or “We'll all be killed?” This is the essence of positive thinking. It doesn't offer guarantees, but it gives you your best chance.

Losers focus on what's difficult until all they see are problems. Positive thinkers think about what's possible. In concentrating on the possibilities, they make things happen.” (p. 101.)

Reconnecting Spiritually: This included both traditional faith-based activities, as well as engaging in meditation, or other culturally appropriate practices that revived or renewed their coping strength, and resilience. This was found to be particularly applicable for those who were African, Asian, Hispanic, or Native American.

Diverting one's focus: Staying busy, is one example of this technique, like Quentin Kenihan referred to on page 94.

⁸ Mactavish, J., & Iwasaki, Y. (2005) Exploring Perspectives of Individuals with Disabilities on Stress-Coping [Journal of Rehabilitation](#).(7) 1; 20-31

⁹ Matthews, A., (2001) being a happy TEENAGER Trinity Beach, Queensland: Seashell Publishers.

Rejuvenating through leisure/exercise: There are two issues here, “Keeping busy” as a way of diverting attention from the worries of life, and the “Value of relaxing”, e.g. listening to music.

1. Related to adjustment to life with a disability, is the challenge of avoiding isolation and keeping up with peers and siblings who do not have a physical disability

This potential isolation can be because of a number of factors including absence from school due to medical procedures, as well as factors like an inability to access places where their peers go, because of a lack of wheelchair access.

For some parent’s this can mean needing to constantly “check out” the homes of school friends, to see if the child will be able to visit them after school or at other times, as these barriers can be a barrier to friendship with peers without a disability.

The following is an example, from Andrew Matthews book “*being a happy teenager*”¹⁰ of someone who despite severe physical disabilities, still manages to have a positive outlook, knows his rightful place in the world, and lives a full life.

Quentin Kenihan

Twelve years ago in a restaurant in Adelaide, Australia, I met thirteen year-old Quentin Kenihan. He was confined to a wheelchair and his tiny body was the size of a three-year-old.

His father Geoff told me, “Quentin suffers from a rare bone disease, osteogenesis-imperfecta. His body is so fragile that he has had 300 broken bones since birth. He has spent half his life in hospital.” Geoff said, “We had steel rods put in his legs to try and help him walk. But his muscles are too weak to support him.”

I remember wondering, “What is this kid going to do with his life?”

Now 26, Quentin would still be three feet tall - but he is unable to stand. In the last 12 years he has broken 328 more bones - about every bone in his body except his neck. He gets more pain in a week than most people get in a lifetime. He was also run over by a car in 1999.

But that hasn’t stopped Quentin. He is currently studying for a degree in film making at Flinders University. He says, “I know what I want to achieve. I may never get there but the journey sure is fun!”

His last job was in marketing and now Quentin has his own media production company. He has already made television commercials, two short films and two documentaries. He has written scripts for other films.

He now lives by himself. He needs help to get out of bed, he needs help to wash and dress himself. His family and a lot of caring people support him.

¹⁰ Matthews, A., (2001) *Being a Happy Teenager*, Trinity Beach, Queensland: Seashell Publishers.

They support him because he has guts, a great sense of humour and a huge fighting spirit.

People help Quentin because he helps himself.

My wife, Julie, spoke to Quentin last week. He was back in hospital with a fracture in his back. Five days later he flew to L.A. to film the Oscars. What a guy!

Says Quentin, "The more time you sit around the house and bitch about "why not - the less time you spend going out and doing it (p118-19.)

It has been suggested that parents can foster independence by doing the following from an early age;

- Allow your child to make choices. Parents can help children make appropriate choices by giving them controlled options.
- Share your belief in the importance of fostering self-determination skills with the providers or community leaders who also are interacting with your child.
- Ask your child about his or her hopes for the future.
- Talk with the professionals who are providing services to your child about including opportunities for your child to develop and practice the daily living skills that will help him or her to live as independently as possible as an adult.
- Remember that home, school and community all provide opportunities for children to learn, make choices and solve problems.¹¹

¹¹ Page 32, Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook, Paul H. Brookes Publishing Company Inc. Baltimore: MA.

Resources:

ASBAH's independent living pack – Make it Happen
[British Association for Spina Bifida and Hydrocephalus.]
<http://www.asbah.org/Publications/Independent%20Living%20Pack.html>

Baker, Bruce, L., & Brightman, Alan J., with Blacher, Jan, B., Louis J. Heifetz, Louis J., Hinshaw, Stephen, R., & Murphy, Diane, M., (2004) Steps to Independence: Teaching Everyday Skills to Children with Special Needs. Baltimore: Ill., Paul H Brookes Publishing Company. [ISBN: 1-55766-697-0]

CALM Parkfinder [Includes **Universally Accessible Facilities Provided** – section to find wheelchair accessible sites.]
http://www.naturebase.net/national_parks/database/parkfinder.html

Matthews, A., (2001) being a happy TEENAGER Trinity Beach, Queensland: Seashell Publishers.[See also publishers' website www.seashell.com.au]

Sandler, Adrian, M.D. (2004) Living with Spina Bifida: A Guide for Families and Professionals. (Updated Edition. With a New Preface by the Author.) NC: University of North Carolina Press [ISBN 0-8078-5547-2.]

Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook. Paul H. Brookes Publishing Company Inc. Baltimore: MA.[See also the publishers' website <http://www.brookespublishing.com/>]

World Association of People with Disabilities [Chatroom for Children with Disabilities]
www.wpd.org

Wheelchair Sports Association <http://www.wheelchairsportswa.org.au/>

