

CHALLENGES TO EMPLOYMENT - PERCEPTIONS AND BARRIERS AS SEEN BY PEOPLE WITH DOWN SYNDROME AND THEIR PARENTS

by

John Grantley, Roy Brown and Judy Thornley

Abstract

This paper is concerned with aspects of employment for 14 young persons with Down syndrome who wished to transition from school to work. It particularly focuses on employment and discusses the implications for individual quality of life. A questionnaire was developed and given in interview format to the young people with Down syndrome, while the parents completed a similar questionnaire. The results suggest that the young people were interested in employment, and had many employment ideas of a practical nature. They provided a wider range of interests than those suggested by parents, but the latter had a much clearer idea of needs and experiences they would like their child to obtain through employment. Families frequently did not know how to access employment or employment experience for their children, and this was not provided to any large degree by the schools which the children attended. It is suggested that teachers require more knowledge of the changing life expectations for people with Down syndrome and greater knowledge of their potential success. The results are discussed in terms of a quality of life model, illustrating how wellbeing can be attenuated when any one aspect of experience is limited. A number of practical recommendations are made.

Introduction

The project described in this paper is a collaborative venture carried out by a research team from the School of Special Education and Disability Studies, in conjunction with the Down Syndrome Society of South Australia Inc. and Interwork Limited. The research is based on a quality of life and wellbeing model (see Brown, 1997 and Goode, 1994) and is concerned with the expressed choices and preferences of people with Down syndrome regarding their post school life experience. This paper is particularly concerned with the perceptions of young people with Down syndrome and their parents, in particular their employment preferences and some of the challenges to employment that may confront them.

Quality of life is a sensitizing concept (Taylor, 1994), which is directed to viewing disability in new ways. Specifically, it is now recognised that the perceptions of and choices by persons with disabilities should play an important role in the development of programmes (Brown, Bayer and Brown, 1992). There has not been any consistent application of the integrated principles of quality of life to the educational system (see

Hegarty, 1994, Brown and Shearer, 1999), yet the relevance of such principles such as holism, self image and empowerment appear to have relevance to education and require systematic examination in terms of curriculum and teaching practice. Lifespan issues are also important and underscore critical aspects of development for people with intellectual disabilities (see Brown, 1997). A number of recent articles in Exceptionality Education Canada (1999) have highlighted the need for such application

The current article concerns one aspect of quality of life for teenagers with Down syndrome, namely, the area of employment, and sets out to see how the principles of quality of life (Schalock et al, 2000) apply in this situation. It looks at some of these issues from the perspective of both the people with Down syndrome and their families. The study recognises the importance of the separate perceptions of these two stakeholder groups. It is recognised that the two groups may have very different perceptions and that proxy statements given on behalf of one group for the other would be unacceptable (Cummins, 1997). The issue is not one of accuracy from an external point of view, but the importance of perceptions held by the individuals concerned, and the relevance of these to educational and employment practices.

The project involved fourteen young people with Down syndrome, who were interviewed before they obtained employment and are subsequently being monitored as they progress towards open employment. This paper explores issues such as, the individual's reasons for wanting employment and where they would like to be employed. The type of work experience provided at school, the perceived barriers to employment and the perceived need for further training, were also explored.

In addition to the individuals being interviewed the parents were also sent questionnaires and the information from these are discussed in relation to the views expressed by the people with Down syndrome.

Research questions

1. Identify the preferences and desires of people with Down syndrome in regard to their future employment opportunities.

2. Identify the other learning needs and interests of people with Down syndrome.
3. Compare the preferences and desires of people with Down syndrome with those of their parents.
4. Establish the extent to which schools and employment placement agencies have responded to the preferences and desires of people with Down syndrome.

Method

Sample and Procedure

The research project involved fourteen young unemployed people with Down syndrome (5 males and 9 females) and their parents. Each of the unemployed young people were registered with an employment placement and training agency. The young people with Down syndrome ranged in age from 18 years and 1 month to 29 years and 8 months (Average age: 21 years and 6 months) and all but one lived at home with their parents (13). The other person lived in a community residential unit with a room mate who also had an intellectual disability. Eight of the people with Down syndrome (4 females and 4 males) were educated in Special Schools while six (5 females and 1 male) had attended regular schools (see Table 1.).

Table 1. Consumer Demographic Information

1	M	19yrs 2mths
2	M	19yrs 3mths
3	F	19yrs 1mth
4	F	19yrs 2mths
5	F	22yrs 4mths
6	M	29yrs 8mths
7	F	18yrs 5mths
8	F	25yrs 8mths
9	F	19yrs 9mths
10	F	19yrs 4mths
11	M	18yrs 1mth
12*	M	28yrs 1mth
13	F	20yrs 7mths
14	F	23yrs 11mths

(9 Females) (Average Age)

(5 Males) (21yrs 7mths)

Range 18yrs 5mths - 29yrs 8mths

Residential status: all in parental home with one exception (residential unit of disability services*)

The people with Down syndrome were interviewed about their attitudes to employment, their perceptions and expectations of work, their knowledge of opportunities for employment and available training, and their preferences concerning leisure time activities. While the interviews were in progress, the parents were requested to complete a questionnaire which had parallel questions to the interview schedule utilised with the people with Down syndrome so that direct comparison of responses could be made. The parallel questionnaires completed by the parents enabled the researchers to compare and contrast the responses, as well as verify that the responses collected during the interviews were valid.

In most cases the mother of the person with Down syndrome was the respondent to the questionnaire (13 out of 14). Only one father was the respondent to the questionnaire, although fathers were present at most of the initial interviews. While the parent completed the questionnaire the person with Down syndrome was interviewed to avoid direct and indirect parental influence on responses.

Questionnaires

Two parallel questionnaires were produced. The design was based on the previous questionnaire development of such authors as Brown and Bayer (1992), Halpern (1994) and Renwick, Brown and Nagler (1994) Each questionnaire consisted, of twenty questions of a parallel nature (eg Parent Questionnaire: *What sort of training do you think your son / daughter would need to get a job.* People with Down syndrome Questionnaire: *What sort of training do you think you would need to get a job?*) The questions were presented to the people with Down syndrome in an interview format in their own home while the parents were requested to complete the questionnaire in another room. The questions covered the following areas: employment opportunities, support and training, work associated skills and barriers to employment.

There were 12 open questions (eg *What sort of job would you like to get?* : question presented to person with Down syndrome) and 8 closed questions (eg *Do you know where they can get this sort of training?* : question included in parent questionnaire). Two of the closed questions included additional open ended questions (eg *Do you think that you will get a job now or in the future?* Followed up with: *Why or Why not?*) The Questionnaires were trialled with two people with Down syndrome and their parents. No changes were made to the original questionnaires and the data collected during the trial were included in the research project.

Results and Discussion

Presented below are some of the interview responses by people with Down syndrome concerning their employment prospects and these are compared with those of their parents. The data indicate that there is some agreement between

people with Down syndrome and their parents concerning the type of employment their sons or daughters have an interest in, whereas there does appear to be some differences in the reasons given for wanting employment.

The following range of reasons for gaining employment were presented by people with Down syndrome and their parents (see Table 2.).

Table 2. Why would you like to get a job? *

(Why would you like your son/daughter to get a job?)

Reasons for wanting a job	Person with Down Syndrome (n=14)	Parent (n=14)
Form relationships	4	2
Perform tasks or roles	10	2
Earn money	1	0
Personal well being	4	10
Don't know	2	0

*Note some people with Down syndrome gave more than one response.

People with Down syndrome emphasised their reasons for wanting work in terms of their interest in having the opportunity to perform specific tasks or valued roles in employment, and to a lesser extent, establishing relationships and their personal well being. Their parents tended to emphasise the need for personal development, and this related to independence, self-esteem and personal well being. The parents were more concerned about the person and their level of satisfaction rather than the type or status of the employment. The people with Down syndrome were more concerned with the type of work they would like to perform.

Some examples of the parents' responses to the question; "Why would you like your son or daughter to get a job?" were: *"To maintain a level of self esteem and independence"*.

and

"Because I do not want her at home doing nothing after she finishes school".

Some examples of the responses people with Down syndrome gave to the question: "Why would you like to get a job?" were:

"Because I'll be able to be a nurse".

and

"I can't wait, because I will be helping - make food, washing dishes".

It was further indicated that people with Down syndrome were more concerned with the specific tasks and roles in which they would like to be involved when asked about the type of job they would like to get. The jobs nominated by parents could be categorised into 10 categories whereas 17 categories were chosen by consumers. Parents tended to select the more traditional type of jobs considered suitable for people with intellectual disabilities (see Table 3.), whereas the person with Down syndrome suggested a wider range of employment considerations than their parents.

Table 3. What sort of job would you like to get?

(What sort of job would you like your son/daughter to get?)

Job type categories	Person with Down Syndrome (n=14)	Parents (n=14)
Clerical Assistant	4	4
Cook/Chef Food Preparation	4	1
Supermarket stacker	1	1
Computer Operator	1	1
Writer	1	1
Actor	1	1
Music Industry	0	1
Gardener	0	1
Library Assistant	0	1
Cleaner	0	1
Fast Food assistant	2	0
Shop assistant	1	0
Child Carer	1	0
Checkout Operator	1	0
Nurse	1	0
Waiter	1	0
Zoo Keeper	1	0
Dancer	1	0
Choreographer	1	0
Factory Worker	1	0
Editor	1	0
Total Job Type Categories	17	10

While there were only four (4) instances where the person with Down syndrome named the same job as their parent, it was noticeable that parents gave characteristics of work (eg “a safe environment, indoor work, within capabilities, within the community and opportunities to meet people”). It can be concluded that individuals with Down syndrome name a wider range of specific jobs than parents. This suggests that a broader choice selection should be recognised by counsellors and teachers, based on each individual’s interests. However, it should be noted that parents were able to define characteristics of work more clearly, and these views, too, should form part of the counselling and exploration process..

People with Down syndrome and their parents overwhelmingly indicated the type of work activity expected to be gained was a job in open employment with the necessary supports (See Table 4). Only a small group aspired to have a job in Sheltered Employment. In addition, some parents indicated that they would prefer the person with Down syndrome to gain unpaid work in the community rather than paid work in Sheltered Employment. Four of the people with Down syndrome were involved in unpaid voluntary work, but none indicated this to be their preference.

Table 4. What type of job activity do you think you will be able to get, now or in the future?

*(What type of job activity do you think your son/daughter will be able to get, now or in the future?)

Type of job placement	Person with Down Syndrome (n=14)	Parents (n=14)
Open employment (without support)	1	3
Supported employment (open employment with support)	9	13
Sheltered employment (Workshop)	3	4
Voluntary Work (Unpaid Work)	2	5

* Note some people gave more than one response.

The people with Down syndrome were asked to recall the range of work experience placements that were completed while they were at school. Their parents were also asked to respond to a similar question to substantiate and add to the range of responses recorded. The Range of work experience placements completed while at school by people with Down syndrome are detailed in Table 5, and in this case represent combined student and parent commentaries as there was high agreement.

Table 5. What sort of work experience did you do at school?

(What sort of work experience did your son/daughter do at school?)

Work Experience	Number of Responses	Percentage of Field Placements
Community Based Employment	19	46%
School Based Employment	10	26%
Sheltered Employment Based	12	29%
Total	41	100%

The responses concerning the range of work experience completed while at school indicate that the people with Down syndrome were placed in Community Based Employment only 46% of the time whereas they were placed 29% of the time in Sheltered Employment or failing that in School Based Employment, 26% of the time (See Table 5). This was confirmed by parents. Although people with Down syndrome and their parents indicated that they expected employment to be in the community with the appropriate support, less than half the school work experience placements took place in the community.

Of the 19 (46%) Community Employment work experience placements shown in Table 6, only 12 work experience locations were utilised, and 4 of these 12 work experience locations were organised by a parent for one of the people with Down syndrome. The remaining 8 work experience locations were arranged for students by schools.

The range of jobs nominated by the people with Down syndrome was quite varied and certainly more wide ranging than that proposed by their parents (see Table 3), and is supported by the observations by Brown et al. (1992) in their quality of life research indicating that the variability amongst consumers is considerable and is more diverse than carers think is possible.

The range of work experience provided by schools appears to be quite limited when compared with the wide range of preferences and expectations listed by people with Down syndrome and to a slightly lesser extent by their parents . It also appears that less than half those work experience placements organised by schools were community placements or placements in open employment with support. As indicated previously, it was the preference of people with Down syndrome and their parents that the type of job they would prefer now or in the future would be in open employment with support. This suggests that greater consideration of the preferences

expressed by people with Down syndrome and their parents might lead to a greater range of work experience placement and an increased focus on community locations, rather than sheltered or simulated environments.

Table 6. Range of Community Based Work Experience Locations while at School

Placement Location	Number of Placements
1. Music Shop	1
2. Public Library*	2
3. Nursing Home	4
4. Screen Printing	1
5. Recreation Centre*	1
6. Local Newspaper*	1
7. Kindergarten*	2
8. Kitchenwork	2
9. Canteen	1
10. Hardware Store	1
11. Supermarket	2
12. Car Detailing	1
Total	19

(* Locations organised by a parent)

The people with Down syndrome and their parents were asked to list what they considered the most important training requirements outside those for obtaining and retaining a job. The people with Down syndrome and their parents emphasised similar areas of training need, which included social skills, self-help skills, grooming, independent living skills, academic skills and budget training. Although the people with Down syndrome emphasised the need to develop friendship skills and social skills their parents did not indicate the same emphasis, although the parents did put a little more emphasis on marriage preparation (see Table 7).

Both parents and people with Down syndrome agreed that there is a need for further training in the following areas:

- Budget training
- Independent living
- Academic skills
- Self help skills
- Relationship and Sexuality
- Public Transport

The expression of further training needs of the people with Down syndrome and their parents suggests a broad spectrum of skills that might be focused upon at school, and particularly during the transition years from school to employment. It also points to the fact that parents should be consulted and involved actively in the transition period from school to work. The skills listed as priorities, are not specific work skills but those skills which are related to a person's quality of life including their self esteem and personal well being. If these do not receive attention it seems likely that failure may occur. Quality of life models stress the importance not only of responding to individuals' perceptions and choices, but also recognising the principle of holism whereby learning and performance in one area is likely to improve performance in other areas (Brown, Bayer and Brown, 1992). The nature of some of these other skills can be seen in Table 7 and it is argued that these need to be developed in School prior and during the transition years, and will still likely need to be supported once employment takes place.

It is of interest that the levels of need are fairly similar amongst persons with Down syndrome and their parents with the exception of social and friendship skills. Parents saw greater need in the former while people with Down syndrome highlighted the latter. It is possible the two are related. However, the concerns over lack of friendships noted in the literature (Firth and Rapley, 1990; Denholm, 1992), which not only stress the need for people with intellectual disabilities to learn how to develop friendships, also underscore that the needs for friendship amongst persons with Down syndrome are very similar to other adolescents. One of the major challenges is that failure to move from school to employment tends to restrict or even cause deterioration in peer age friendships making it even more difficult to enter young adult life. Employment and social skills are mutually supportive or restricting, depending on the changes which take place and it is recommended that schools and parents consider further how these might be included during the secondary years, in particular.

Although people with Down syndrome and their parents were able to clearly state their perceived training requirements, only 56% of the parents and 28% of the people with Down syndrome indicated that they knew where to access vocational training (see Table 8). Riches (1996), states emphatically that there is a "lack of information on just what services are available post school, as well as an inadequate number of appropriate high quality adult services..." Whether the responses in this research indicates an unawareness of the sources of vocational training currently available or suggests that appropriate quality vocational training is not being offered, needs further investigation. Wherever appropriate vocational training is currently available, it needs to be documented, publicised in plain English and disseminated through schools and disability service agencies to all relevant consumers and their families.

Table 7. What besides job training are your other learning needs?

(What besides job training are your son's / daughter's other learning needs?)

Type of job	Person with Down Syndrome (n=14)	Parents (n=14)
Social Skills	11	4
Self Help Skills	10	9
Independent living skills	10	12
Public Transport	7	10
Leisure and recreation	8	5
Friendship skills	11	3
Relationships and Sexuality skills	9	9
Marriage preparation	8	11
Academic Skills	11	8
Budget Training	11	13
Grooming Skills	11	7

Table 8. Do you know where you can get this sort of training ? If yes, where ?

(Do you know where they can get this sort of training ? If yes, where ?)

Source of Training	Person with Down Syndrome (n=14)	Parents (n=14)
Tertiary Sector - (eg TAFE, University)	2 (14%)	3 (21%)
Employment placement agency	0	4 (28%)
Supported employment agency	0	1 (7%)
School	2 (14%)	0
No response	10 (72%)	6 (44%)

This study has underscored a number of concerns which have considerable practical implications. Yet they also point to the need for greater understanding of :-

- 1) the fact that adolescents with Down syndrome wish to obtain employment.
- 2) the difficulties which occur when schools do not provide strong links for adult types of experience for independent or supported community employment .
- 3) the limiting effects on adolescents if allied skills of a social and self help nature are lacking.
- 4) the impact that lack of employment opportunities are likely to have on friendship and social interaction.

Seeking opinions from adolescents and young adults with Down syndrome is critical. Not only does such an approach recognise they are the primary stakeholders, but enhances their well being through many quality of life principles. (Schalock et al, 2000). Their perceptions and choices need to be recognised, and if handled sensitively such an approach is likely to enhance self-image and empowerment. Thus we may expect motivation and performance to be enhanced. The quality of life model suggests that limitations in these areas are likely to impact negatively on other domains of wellbeing, such as health, home living and recreation, as well as curtail the individuals' development of choices, self image and empowerment, as well as having life span effects (Brown, 1997, Renwick, Brown and Nagler, 1996). In other words, lack of appropriate development in employment is likely to impede satisfactory opportunity and adaptation in other areas. This is particularly disturbing given the increasing lifespan of persons with Down syndrome which averages beyond 55 years (Baird and Sadovnik, 1987). Schools and teachers are the gatekeepers to this extended life and can open opportunities to improve their students future wellbeing if aware of and skilled in promoting employment opportunities.

There are risks and challenges in doing this. Individuals may be disappointed in their choices, not all developments will be successful, and parents and teachers may disapprove of the individual's choices and sometimes prevent them being operationalised. Expectations are easily set up which may not be met. However, wellbeing requires personal control as a critical element, and exploration of the kind presented in this article is one way of encouraging dialogue and exploration. Provided this is done with supportive, caring, but not overbearing, structure, positive changes are likely to take place.

Conclusions

This research project has shown that if people with Down syndrome and their parents are asked their opinions about current and future employment expectations and aspirations they are able to give positive and optimistic responses that are wide ranging and challenging. It is suggested that the preferences of people with Down syndrome, as well as those of their parents, are given high priority when considering

employment opportunities, particularly in the selection of work experience and the location of those work experience placements. When seeking employment opportunities for people with Down syndrome, their preferences and choices should be given the most serious consideration and perhaps, higher priority than their parents and teachers. To satisfy the vocational preferences of the people with Down syndrome and their parents it is suggested that more consumer directed vocational programs be developed (Agran, Test & Martin, 1994).

The currently available vocational training programs should be publicised widely to ensure all consumers are well informed. People with Down syndrome have shown that they are able to articulate their aspirations, preferences and needs for their working lives. If they are provided with the relevant information regarding available vocational opportunities and training programs then they will be able to make more informed and effective choices, giving them more control over their future employment opportunities. These are two significant characteristics which contribute to an improved quality of life.

Finally, the study underscores some of the restrictions affecting the development of quality of life for persons with Down syndrome in the late adolescent and young adult years. The danger is that lack of knowledge by teachers, parents and people with Down syndrome in various ways restricts opportunities and choices in the employment field. It is also associated with limiting development of other areas of well being, such as social skills and friendship development, which not only need considerable support during the school years but need to be highlighted within the employment process. It is essential that teachers understand the lifespan effects when adolescents with Down syndrome are not sufficiently supported in moving to community employment.

Acknowledgement

We are grateful to the Down Syndrome Society of South Australia for their support and assistance.

References

Agran, M., Test, D. & Martin, J. (1994). Employment preparation of students with severe disabilities (Ch.7), pp184-212. In E. Cipano and F. Spooner, *Curricular and instructional approaches for persons with severe disabilities*. Massachusetts: Allyn & Bacon.

Baird, P. A. & Sadovnik, A. D. (1987). Life expectancy in Down syndrome. *Journal of Paediatrics*, 110, 849-854.

Brown, R.I. (1997). *Quality of Life for People with Disabilities*. Cheltenham, UK: Stanley Thornes.

Brown, R.I. & Shearer, J. (1999). Challenges for inclusion within a quality of Life Model for the 21st Century. *Australian Journal of Special Education*, 22, 180-194.

Brown, R.I., Bayer, M.B. & Brown, P.M. (1992). *Empowerment and Developmental Handicaps: Choices and Quality of Life*. Toronto, Ontario: Captus Press.

Cummins, R.A. (1997). Assessing Quality of Life. In R.I. Brown (Ed) *Quality of Life for People with Disabilities*. 2nd Ed, pp116-150, UK: Stanley Thornes.

Denholm, C. (1992). Developmental Needs of Adolescents with Down Syndrome. In R.I. Brown (Ed.) *Building our Future*, pp125-133, Calgary, Canada: National conference of the Down Syndrome Society.

Exceptionality Education Canada. (1999). 9 (1&2), 1-171.

Firth, H. & Rapley, M. (1990). *From Acquaintance to Friendship: Issues for Persons with Learning Disabilities*. Kidderminster : BIMH Publications.

Goode, D. A. (Ed.) (1994). *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. Cambridge, MA: Brookline.

Halpern, A. (1994). Quality of Life for Students with Disabilities. *Social Indicators Research*, 33, (1-3), 193-236.

Hegarty, S. (1994). *Quality of Life at School*. In D Goode (Ed) *Quality of Life for Persons with Disabilities : International Perspectives and Issues*, pp241-249. Cambridge, MA: Brookline.

Renwick, R. Brown, I & Nagler, M (Eds.) (1996). *Quality of Life in Health Promotion and rehabilitation : Conceptualizations, Research and Applications*. Thousand Oaks, CA: Sage.

Riches, V. (1996). *Transition from School to Community* In B. Stratford and P. Gunn (Eds), *New approaches to Down syndrome*, pp424-435. London: Cassell.

Schalock et al (In press). *The Conceptualization, Measurement and Application of Quality of Life: Results of an International Consensus Process*. IASSID Special Internet Group. Washington DC: AAMR.

Taylor, N. (1994). In support of research on quality of life, but against QOL. D. Goode (Ed), *Quality of life for Persons with Disabilities: International Perspectives and Issues*, pp260-265. Cambridge, MA: Brookline.

John Grantley*

Roy Brown

Judy Thornley

*Contact

School of Special Education and Disability Studies
The Flinders University of South Australia
GPO Box 2100
Adelaide, SA, 5001
Australia

Email: john.grantley@flinders.edu.au