

ORIGINAL ARTICLES

**EMPLOYMENT LEADS TO INDEPENDENT LIVING AND
SELF-ADVOCACY: A COMPARATIVE STUDY OF EMPLOYED
AND UNEMPLOYED PERSONS WITH COGNITIVE DISABILITIES**

Raj Narayan Sharma*, Shobra Singh**, A.T. Thressia Kutty***

ABSTRACT

The main purpose of this study was to measure the effect of employment on independent living and self-advocacy of persons with cognitive disabilities. The other purposes of the paper were to measure the effect of severity of disability and type of employment, on self-advocacy skills and independent living skills. A ten item-five point rating scale was developed to measure the independence level and self advocacy of persons with cognitive disabilities. A qualitative and quantitative study of fifty unemployed and fifty employed persons with cognitive disabilities was carried out. The results were statistically analysed and a significant difference was found between the groups, with the unemployed persons with cognitive disabilities scoring significantly lower in independent living and self-advocacy skills. Those in open employment showed more independent living and self-advocacy skills than those in group employment. The practical implications of the findings of this study are discussed.

INTRODUCTION

An exciting and powerful world-wide development of late is that groups of people with mental handicap have been taught to organise their affairs, arrange meetings, make decisions and carry them out, with minimal help from non-handicapped people. This development is termed as “self advocacy”.

An examination of the research on self-determination and self-advocacy reveals an overlap in definitions. The two words are often used interchangeably when discussing students

advocating for themselves. Field, Hoffman, and Posch (1) defined self-determination as “the ability to identify and achieve goals based on the foundation of knowing and valuing oneself” (p. 287). According to Pennell (2), self-advocacy focuses on the ability to stand up for oneself and to help other people with disabilities stand up for themselves by speaking up, speaking out, and speaking loud. It means having the opportunity to know one’s rights and responsibilities, to stand up for them, and to make choices about one’s own life.

The authors conducted a literature search with the keywords “employment outcome/open employment” and “cognitive disabilities”. Sixty-five and twenty-seven articles were found for each set of key words. The articles were read by both the authors and sorted according to the relevance of the topic. Ten studies were thus sorted in the process.

More recently Price, Wolensky, and Mulligan (3) referred to self-determination as a complex set of skills and educational outcomes that can be taught anywhere and at any time to students with disabilities. However, just knowing about self-determination is not enough. Students must learn how to be self-advocates in school and the real world, and self-determination skills must be practised on a daily basis to be successful. For the purpose of the study, the term “advocacy” means speaking or acting on behalf of oneself or others, or on behalf of a particular issue. Self-advocacy by people with cognitive disabilities means that individually or in groups, preferably both, they speak or act on behalf of themselves, on behalf of issues that affect people with cognitive disabilities.

In the past few decades, numerous researches have been done in the field of self-advocacy and mental retardation. Relatively few researches authentically support the fact that one of the greatest outcomes of employment is self-advocacy and independent living skills. Self-determination is a culturally determined concept and cultural values influence one’s definition of self-determination (4). In line with their overlapping nature, it could be presumed that the concept of self-advocacy too is influenced by the cultural aspects of persons with disabilities. India is still in an evolving phase of teaching self-advocacy skills and higher levels of self-independent living skills to persons with cognitive disabilities. This is primarily because of growing needs of inclusion both in school and employment. According to Kiernan (5), employment is a way in which individuals support their lifestyles, develop friendships and identify themselves as individuals. In conjunction with the growing evidence that people with

disabilities continue to experience social isolation, high unemployment, and low economic status, and based on anecdotal information provided by self-advocates and others with disabilities, one can presume that people with cognitive disabilities have limited opportunities to be self-advocating. The focus of quality open employment dictates that services result in meaningful employment outcomes for persons with significant disabilities. The group form of employment has had many disadvantages regarding employment outcomes (6).

The major objectives of the study were to prepare an assessment scale to measure the independent living and self advocacy skills of persons with cognitive disabilities, to identify employed and unemployed adults above eighteen years of age and to administer the developed scale on them, to analyse the data and find out the differences between the two groups in achieving independent living and self advocacy skills and to evolve suggestions based on the study. Questions were selected in an effort to determine the extent to which respondents would be considered as being self-advocates. The questions for developing the scale were adapted from the study done by Wehmeyer and Metzler in 1995 (7). For the present study, the authors adapted the instrument in accordance with the cultural and socio-economic status of the region to be studied.

METHOD

Participants

Participants consisted of a hundred adults (24 females, 76 males) with developmental disabilities, with mild and moderate levels of functioning in accordance with the Persons with Disabilities Act (PD Act) of government of India. The PD Act uses the following definition, 'mental retardation means a condition of arrested or incomplete development of mind of a person which is specially characterised by sub normality of intelligence'. Mild retardation is defined by IQ level of 50 to 69, and moderate by IQ level of 35 to 49.

In accordance with study aims, half of the participants were employed at the time of the study. For the purpose of the study, criteria for considering employed and unemployed was decided. Any person working in the private or public sector getting wages was considered employed. All the persons in the employed group were working in various settings in the twin cities of Hyderabad and Secunderabad in southern India, at the time of study. An unemployed person was one who was still getting training with or without some kind of remuneration. For

the ease of selecting participants, all in an unemployed group were selected from the vocational training centre of the National Institute for Mentally Handicapped, Secunderabad. All the trainees here are given remuneration in the form of an hourly wage and bus fare.

The average age of participants in the employed group was 36 years (standard deviation 9.1) and the unemployed group was 29 years (standard deviation 8.4). The gender and functional levels of the two groups are presented in Table 1. The gender proportions were equal in the two groups, $\chi^2 (1, N = 100) < 1$, and they did not differ significantly in functional levels.

Table 1. Gender and functional levels of the groups

Characteristics	Employment Status		
	Employed		Unemployed
	Open	Group	
Gender (%)			
Male	19	19	38
Female	6	6	12
Functional Level (%)			
Mild	18	17	35
Moderate	07	08	15

Instrument

The authors developed an instrument called the “Ten Item - Five Point Rating Scale”, designed in the form of a scale to measure the self-advocacy and independent living skills of adults with cognitive disabilities. Initially it was tested on ten subjects and modified. The details of the scale are given in Appendix-1. All the subjects were individually contacted at their work place by the authors. Each item in the scale was further divided into 4 observable and measurable skills to make the scoring easy. The item-wise data were entered individually in the score. Each item was rated on a five-point scale (4= all four sub items correct, 3 = three sub items correct; 2= two sub items correct; 1= one sub item correct, 0 = no sub item is correct). The internal reliability of the English version was relatively high, (Cronbach alpha = .86).

The questionnaire was translated into the widely spoken local languages of Hindi and Telugu. The tool was validated in both languages and the total scale reliability was satisfactory. An item about married life was deleted because it was irrelevant. Other questions that were irrelevant to the present study were also deleted.

Procedure

The one hundred adults with mental retardation participating in the study were each interviewed individually either in their work place or at home. The interviews were conducted after obtaining agreement for participation and providing a detailed explanation of the study. The interviewer read each question and response options and marked the participant's replies. The participants were assured of the confidentiality of the information, and the data were coded and analysed without personal identification.

RESULTS

The authors had postulated three hypotheses for the study.

Hypothesis 1- Employment leads to independent skills and self-advocacy skills.

Hypothesis 2- Open employment has greater effect on inculcation of self-advocacy skills than supported/group employment.

Hypothesis 3- Persons with mild cognitive disabilities have more self-advocacy skills than persons with moderate cognitive disabilities

Table 2 represents the number of employed and unemployed persons with mental retardation, mean, standard deviation and also the minimum and maximum point scored by each group.

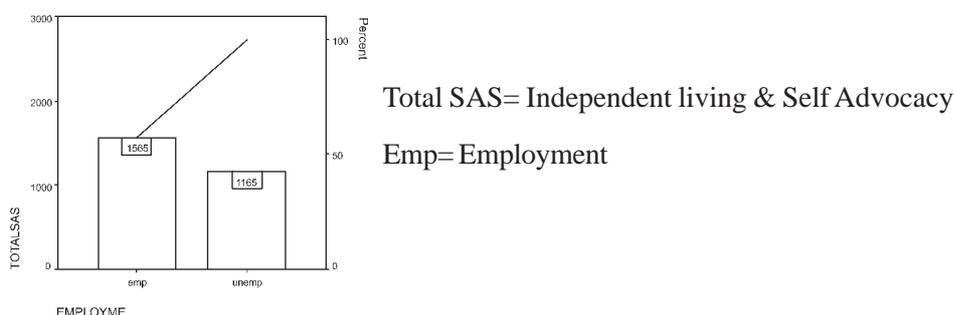
Table 2. Relationship between employment, and independent living and self advocacy

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Emp	50	31.3000	4.87915	.69002	29.9134	32.6866	23.00	40.00
Unemp	50	23.3000	3.30892	.46795	22.3596	24.2404	17.00	31.00
Total	100	27.3000	5.77613	.57761	26.1539	28.4461	17.00	40.00

A one way (ANOVA) applied to the ten item five point rating scale revealed that employment has a significant effect on inculcation of self advocacy and independent living skills [$F(1600, 1703) = 92.073; p < .0001$].

Graph 1 presents the means of the self determination subscales and total scales for the 2 groups.

Graph 1.



Confirming the first hypothesis, the study found a higher level of self-advocacy skills among employed than unemployed participants.

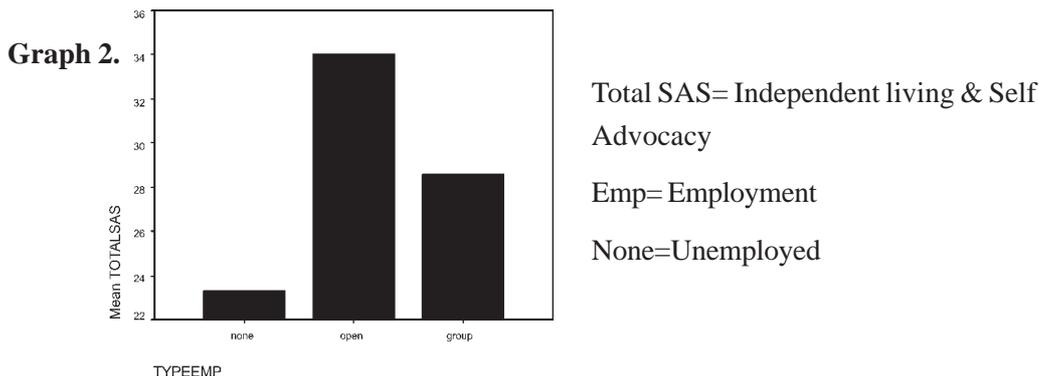
Table 3 presents the means and standard deviation for open and group employment.

Table 3. Relationship between types of employment, and independent living and self advocacy

Descriptives

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Unemployed	50	23.3000	3.30892	.46795	22.3596	24.2404	17.00	31.00
Open	25	34.0000	4.23281	.84656	32.2528	35.7472	26.00	40.00
Group	25	28.6000	3.93700	.78740	26.9749	30.2251	23.00	38.00
Total	100	27.3000	5.77613	.57761	26.1539	28.4461	17.00	40.00

The results of a ANOVA test applied to open and group employment using the scale showed significant effects for independent living and self advocacy skills in open employment than in group employment [$F(1964.500, 1338.500) = 71.183, p < .0001$].



The second hypothesis was confirmed, as seen in Table 3 and graph 2.

Table 4 shows the correlation between degree of severity of disability, and independent living and self advocacy.

Table 4. Relationship between degree of disability, and independent living and self advocacy

N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	
				Lower Bound	Upper Bound			
mild	70	28.5714	5.88679	.70361	27.1678	29.9751	18.00	40.00
moderate	30	24.3333	4.29381	.78394	22.7300	25.9367	17.00	35.00
Total	100	27.3000	5.77613	.57761	26.1539	28.4461	17.00	40.00

The results show higher independent living and self advocacy skills in persons with mild cognitive disabilities than in moderate cognitive disabilities [$F(377.190, 2925.810) = 12.634, p < .0001$]. This confirms the third hypothesis.

DISCUSSION

The ultimate aim of rehabilitation is self reliance and independent living. This study confirms that given opportunity and training, persons with mental retardation can earn and talk for themselves. The concept and practice of inclusion is still evolving in India and the general perception is that persons with mental retardation cannot develop self-advocacy skills despite being supported in different ways. This study proves that opportunity to work in open employment conditions leads to self-independent living and self-advocacy skills. It also shows that remunerative employment can lead persons with mental retardation towards a meaningful life. The means and opportunities to enable people with mental retardation to make decisions for themselves should be further developed, and significant efforts should be made both to involve them in all decisions and to minimise the number of matters over which others exercise control (8). Training for self-advocacy should be included as a part of special education curriculum for persons with mental retardation.

However, this is a preliminary study, which had some limitations. The study was limited to Hyderabad and Secunderabad cities, and therefore urban/ rural comparison was not considered. Secondly, the socio economic status and education of the parents were not considered. Thirdly, cross analysis was done only in the area of employment. Further studies are needed to assess if independent living and self-advocacy skills depend on other factors such as job training and also to study the effect of independent living and self-advocacy skills on job sustenance.

*Address for correspondence
Graduate Assistant
Multicultural Scholars Programme
University of Kansas
Lawrence,KS-66045
e-mail: narayan@ku.edu

**Graduate Research Assistant in department of Special Education
Illinois State University, Normal IL, USA
e-mail:ssingh2@ilstu.edu

***Senior Lecturer National Institute for the Mentally Handicapped
Secunderabad, India

REFERENCES

1. Field S, Hoffman A, Posch M. *Self-determination during adolescence*. Remedial and Special Education 1997; 18: 285-293.
2. Pennell R L. *Self-determination and self-advocacy*. Journal of Disability Policy Studies 2001; 11(4): 223.
3. Price LA, Wolensky D, Mulligan R. *Self-determination in action in the classroom*. Remedial and Special Education 2002; 23: 109-116.
4. Turnbull A P, Turnbull H R. *Self-determination within a culturally responsive family systems perspective: Balancing the family mobile*. In L. E. Powers, G. H. S. Singer, and J. A. Sowers (Eds.), *On the road to autonomy: Promoting self-competence in children and youth with disabilities* (pp. 195-220). Baltimore: Brookes, 1996.
5. Kiernan W. *Where we are now: Perspectives on employment of persons with mental retardation*. Focus on Autism and Other Developmental Disabilities 2000; 15: 90-97.
6. Frey J L. *Long term support: The critical element to sustaining competitive employment: Where do we begin?* Psychosocial Rehabilitation Journal 1994; 17(3): 127- 135.
7. Wehmeyer ML, Metzler C. *How self -determined are people with mental retardation? The national consumer survey*. Mental Retardation, 1995; 33(2): 111-119.
8. Duvdevany, H B, Amber A. *Self-determination and mental retardation: Is there an association with living arrangement and lifestyle satisfaction?* Mental Retardation 2001; 40 (5): 379-389.

Appendix 1

Ten Items – Five Point Rating Scale of Measuring, Independent Living and Self-Advocacy Skills

S.No.	ITEM	a	b	c	d	TOTAL
1.	AWARE OF BASIC RIGHTS					
2.	AWARE OF THE RIGHTS OF AN EMPLOYEE					
3.	AWARE OF RESPONSIBILITY OF FAMILY LIFE					
4.	AWARE OF RESPONSIBILITY OF SOCIAL LIFE					
5.	AVAILS PUBLIC FACILITIES					
6.	AWARE OF THE VALUE OF OWN SIGNATURE					
7.	REQUESTS BENEFITS AND CONCESSIONS					
8.	EXERCISE THE RIGHT OF VOTING					
9.	CONDUCTING A SMALL MEETING OF FRIENDS					
10.	APPEALING WHEN RIGHTS ARE DENIED					

Details of Ten Items – five point rating scale for measuring Self-advocacy and Independent living.

- 1) Aware of basic rights
 - a) Selects own food
 - b) Selects own cloth
 - c) Selects own companion
 - d) Selects leisure time activity
- 2) Aware of the rights of an employee
 - a) Asks for wages
 - b) Applies for leave
 - c) Takes interval during work
 - d) Reports the problem on work site
- 3) Aware of the responsibility of family life
 - a) Aware of his place in family life
 - b) Aware of his share in the family property
 - c) Takes care of mother / father /wife / children in need
 - d) Plans and spends
- 4) Aware of responsibility of social life
 - a) Participates in religious activities
 - b) takes part in social function
 - c) Goes out with friends for movie/exhibition
 - d) Visits place for recreation
- 5) Avails public facility
 - a) Aware of the utility of bank
 - b) Uses different means of transport
 - c) Aware of the functions of police station and post office
 - d) Aware of hospitals and rehabilitation centre
- 6) Aware of the value of own signature
 - a) Can maintain his/her own signature
 - b) Request to explain the purpose of signature
 - c) Decides whether it is needed
 - d) Aware of the value of signature (on checks, documents and letters)

- 7) Requests benefits and concession
 - a) Gets and uses bus concessions
 - b) Gets and uses train concessions
 - c) Aware of the provision of father's pensioner benefits
 - d) Aware of loans/schemes for employment
- 8) Exercises the right of voting
 - a) Able to select a leader
 - b) Holds an identity card
 - c) Tells the names of leaders of the country
 - d) Able to select a party or leader for voting
- 9) Conducts small meetings of friends
 - a) Collects few friends together
 - b) Able to discuss about a theme (own problems)
 - c) Write few things regarding the meeting (date, name, people, signature)
 - d) Plans appropriate activity to help a needy friend
- 10) Appealing when rights are denied
 - a) Reports when ill treated at home
 - b) Reports when ill treated at workplace
 - c) Reports when ill treated at public place
 - d) Reports when ill treated at religious place