Journal on Developmental Disabilities
Le journal sur les handicaps du développement

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Editorial Policy

Journal on Developmental Disabilities is published twice yearly by the Ontario Association on Developmental Disabilities (OADD). The Association has established the following objective for the journal:

> *To foster and promote thoughtful and critical dialogue about relevant issues in the field of developmental disabilities, including those broader social issues that impact on persons with developmental disabilities.*

Content

Each issue could feature a selection of research, conceptual, informational, and editorial papers. An issue may have a central theme. Reviews of relevant books, movies, websites, software, and other resources are welcomed, as are letters to the editor. In this way we strive to collectively enrich our understanding of issues, enourage stimulating debate among those working in the field, and improve services.

Language

Submissions are invited in either French or English and, if accepted, will be printed in the language of submission with an abstract in the other language. Submissions must be free of any gender and ethic bias. People-first language (e.g., persons with developmental disabilities) must be used throughout the manuscript (including figures and tables).

Editorial Process

Each submission will be assigned an Action Editor (typically one of the Associate Editors) who will select at least three anonymous reviewers (typically from the Board of Editors) with relevant expertise. The authors of the manuscripts will not be identified to the reviewers. The reviewers will recommend for or against publication and provide their reasons. Reviewers are asked to judge the manuscript on several criteria including its contribution to increasing our knowledge and clarity of communication. The reviewers are asked to write in a positive and constructive manner to help the authors improve their work, if necessary. Reviewers are asked to complete their review within one month.

Final Decision

The Editor-in-Chief reserves the final decision regarding publication of a submission. To promote the publication of theme issues, the Editor reserves the right to decide which issue to publish the article if it had been accepted.

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Volume 6, No. 2

Announcements

Articles

Resource Reviews

Announcements

The *Journal on Developmental Disabilities* is now listed in PsycLit/PsycInfo, the database service of the American Psychological Association.

Call for papers

Special Issue

Organizational Issues in Developmental Disabilities
Guest Editor: W. Larry Williams, University of Nevada, Reno.

Submissions are encouraged that cover relevant topics such as: Service Outcome Management, Process Analysis, Systems Analysis, Service Coordination, Quality Assurance, Staff Training/Management, Cost-Benefit Analyses, Accreditation, Program Evaluation, and related themes. The deadline for submissions is August 1, 1999. Submissions should follow the regular journal format and style guidelines, and be directed to Maurice Feldman, the Editor-in-Chief. For more information about the special issue, please contact W. Larry Williams, Ph.D.; Dept. of Psychology/296, University of Nevada, Reno, Reno, Nevada 89557-0062 USA; phone: (775) 784-1349; email: larryw@unr.edu

Call for Special Topics

Please let us know what special topics you would like to see addressed in the *Journal on Developmental Disabilities*.

Send your suggestions to Maurice Feldman, Editor-in-Chief, *Journal on Developmental Disabilities*, Dept of Psychology, Queen's University, Kingston, ON K7L 3N6.

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Survey of the Need for Speech, Language and Audiology Services Among Adults with Developmental Disabilities Living in the Community

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Barbara L. Stanton, and Sally-Ann Garrett**
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This study surveyed the speech, language and audiology (SL/A) service needs of 559 adults with developmental disabilities served by two community agencies. Caregivers provided information on participant characteristics, sensory functioning, mode of communication, ability to perform eight functions of communication and involvement with SL/A services. In 55% of the cases reported, it was not known if the adult had had a hearing test. Twenty-seven percent of adults were identified by caregivers as needing SL/A assessment or treatment services and 65% of these adults were not receiving these services. Variables associated with service need were examined. Implications for service planning and further research are discussed.

The ability to communicate is an important skill for the successful social adjustment and independence of individuals with developmental disabilities. Unfortunately, difficulties in communication caused by impairments in speech, language or hearing, are extremely common in this group. Delayed or deviant speech, language or hearing development are often considered to be implicit in definitions of mental retardation and autism (Warren & Abbeduto, 1992). Little is known, however, about the actual distribution of speech, language and hearing assessment and treatment needs of adults living in the community. Such information is crucial to the appropriate planning, provision and advocacy of services, and is the focus of the current study.

Previous studies that have attempted to determine the prevalence of speech, language and hearing disorders in individuals with developmental disabilities have reported a wide range of prevalence estimates. Prasher (1995), in a review of prevalence studies, indicated rates of hearing impairments that ranged from 43 to 95% and Keane (1972), in a review of deviant speech patterns revealed rates that ranged from 5 to 94%. Such wide ranges are clearly not specific enough about the SL/A service needs to aid service planners.

The differences in the reported prevalence can, in part, be attributed to differences in the samples, such as in the living environment (i.e., institutional versus community settings), or in the age distribution. As adults with developmental disabilities age, communication skills can deteriorate due to declining perception for speech, declining hearing acuity, acquired physical disabilities, severe aphasia and various dementia such as Alzheimer's disease (Schiefelbusch, 1993).

Differences in living environment can also contribute to discrepancies in reported prevalence. Comparisons of community and institutional-based adults matched for age, sex and level of ability, indicate that adults residing in hospital settings have lower levels of social language competence and are less able to respond to questions. The lower levels of language competence of adults residing in institutions are attributed to living in an environment that does not make sufficient demands to communicate (Brinton & Fujiki, 1994; van der Gaag, 1989).

Much of what is known about speech, language and hearing disorders in this population comes from studies of children, or of adults living in institutions and is therefore outdated or not useful for the many adults who live in community settings. Ontario-based community studies that describe the needs of a large sample of adults with developmental disabilities are needed.

The caregivers of adults with developmental disabilities are often responsible for making referrals for speech, language and audiology (SL/A) services. Such services would include assessment and, if indicated, treatment for speech, language and hearing concerns. Generally, caregivers are considered able to make judgments about the need to refer persons they support for speech, language, or hearing assessments. McLean, Brady and McLean (1996) indicated that caregivers who interact with individuals on a daily basis may have a more complete and representative knowledge of the individual's communicative abilities than the limited information an assessor can gather in one or two sessions. Reichle and Yoder (1979), as reported in McLean et al. (1996), found high levels of consistency between informant data collected by direct-care staff members and direct observational data collected by trained observers. Using direct care staff as informants also has the advantage of providing time and cost savings.

The primary aim of the present study was to determine the need for SL/A services among adults served by two community agencies in the Ottawa-Carleton region in eastern Ontario. A second objective was to determine the variables associated with need for SL/A services. Finally, this study examined the variables associated with receiving services when adults are perceived by caregivers to need them.

Method

Participants

Five hundred and fifty-nine adults served by two community agencies in the Ottawa-Carleton region of Ontario participated in the survey. The participants included adults residing in community living arrangements such as group homes, supported independent living and family homes. None of the participants resided in provincial institutions. Consent was obtained from each individual who participated in the study or from the parents or next of kin of individuals unable to give their own consent. The clinical coordinators for the two community agencies explained the study to each individual, parent or next of kin, and witnessed the completion of consent forms. These clinical coordinators also arranged for the completion of questionnaires by agency direct care staff for the 559 participants.

Data Collection

Questionnaires designed to survey direct care staff on SL/A service need among participants were distributed for each client of two community agencies. Staff were chosen on the basis of their familiarity with the participant, although no information was collected on this variable. Instructions given to staff asked that they respond to the questions as completely as possible but did not specifically ask them to check information in client files if they were unsure of it. The questionnaire was developed by a Speech Language Pathologist from the Queen's University outreach program. It was made up of closed-ended questions and inquired about participants': (a) demographic data such as age, gender, level of mental retardation and associated disabilities; (b) sensory status such as presence of a hearing or visual impairment, (but did not ask how recent such information was); (c) ability to perform eight functions of communication (make social contact; greet, e.g., "hi" or "bye;" tell own name; tell others what to do and regulate others actions; request needs and wants; express feelings; provide information to others and answer questions; respond to instructions; and ask questions to gain information.

These abilities were measured in absolute terms (i.e., does the participant perform the skill or task at all?). The abilities were adapted from Dore's primitive speech acts which is used to identify communicative intent at a basic level (Miller, 1981). It was hoped that this adapted taxonomy would present a window on the individual's communicative intent and ability to participate in social interactions.

The questionnaire also asked about the person's mode of communication such as use of gesture, speech or picture symbols; need for SL/A services (staff's perception); and involvement with speech, language and/or audiological services.

Results

Completed questionnaires were obtained for the 559 participants served by the two community agencies for a response rate of 100%. However, there was some item non-response, particularly to the question regarding level of mental retardation. The number of observations for each variable is indicated in all tables.

Descriptive information

Table 1 summarises age, gender and related descriptive data. The mean age of the participants was 37 years, with a range of 18 to 74 years. Thirty percent of the participants were between 18 and 30 years. Males

Table 1

Descriptive Information on Clients

Variable	Total Variable *n*	*n* (%)
Age (in years)	541	
18 – 30		164 (30.3%)
31 – 40		202 (37.3)
41 – 50		127 (23.5)
51 +		48 (8.9)
Gender	551	
Male		358 (65.0)
Female		193 (35.0)
Level of mental retardation	372	
Mild/Moderate		300 (80.6)
Severe/Profound		45 (12.1)
Unspecified		27 (7.3)
Additional Diagnoses	500	
Psychiatric disorder		131 (26.2)
Down syndrome		76 (15.2)
Cerebral palsy		38 (7.6)
Autism		14 (2.8)

outnumbered females and most participants were in the mild/moderate level of mental retardation (this latter information should be regarded with caution because of a high rate of non-response – 33.5% of the entire sample).

Sensory Information

Table 2 presents the participants' sensory information. Approximately one third of participants were known to have had a hearing test, and for over half of them, the respondents did not know whether the person had had a hearing test. The majority were reported not to have a hearing impairment. Only 5% used a hearing aid.

Table 2
Clients' Sensory Information

	Total Variable	*n* (%)		
Variable	*n*	yes	no	don't know
Hearing impaired	550	47 (8.5)	454 (82.5)	49 (8.9)
Hearing aid	526	27 (5.1)	492 (93.5)	7 (1.3)
Hearing test	555	197 (35.5)	51 (9.2)	307 (55.3)

Eight Functions of Communication

Eighty-four percent of the participants were able to perform at least one function. As shown in Table 3, the function which fewest participants could perform was the ability to "tell others what to do, regulate others actions." The function most participants were able to perform was the ability to "respond to instructions."

Mode of Communication

Table 4 describes the participants' mode of communication. Almost three quarters of the adults were able to communicate using sentences, while 13% communicated using short phrases and word combinations, and

Table 3

Number of Clients Able and Not Able to Perform Functions of Communication

Function of Communication	Total Variable *n*	Able *n* (%)	Not able *n* (%)
Social contact, greet, e.g., "hi" or "bye"	550	513 (93.3%)	37 (6.7%)
Tell own name	551	491 (89.1)	60 (10.9)
Tell others what to do, regulate others action	544	460 (84.6)	84 (15.4)
Request needs and wants	546	499 (91.4)	47 (8.6)
Express feelings	532	482 (90.6)	50 (9.4)
Inform others, answer questions	538	459 (85.3)	79 (14.7)
Respond to instructions	537	523 (97.4)	14 (2.6)
Ask questions to obtain information	544	461 (84.7)	83 (15.3)

8% used only single words. Almost all participants used speech to communicate, and were understood by a familiar caregiver. However, 16% did not have sufficient vocabulary for their environment. Twenty percent used gestures or signs and 10% used graphics and symbols (often in addition to some speech).

Need for, and Receipt of, Speech, Language and/or Audiology Services

Twenty-seven percent of participants were identified as needing SL/A services, and for 15% of the participants, staff did not know if the participant needed services. Eleven percent were currently receiving, and 16% had been referred for, SL/A assessment or treatment services.

Chi-square analyses or Fisher Exact Tests were conducted to determine which variables were significantly associated with needing SL/A services. Significant variables are presented in Table 5, and included Down syndrome, $\chi^2 = 16.32$, $p < .001$; hearing impairment, $\chi^2 = 18.32$, $p < .001$; severe or profound mental retardation $\chi^2 = 15.06$, $p < .001$; not being understood by a familiar caregiver, $p < .002$; and not having sufficient vocabulary for his/her environment, $p < .001$. disorder. The following variables were examined but were not found to be significantly

Table 4
Clients' Mode of Communication

Variable	Total Variable *n*	*n* (%)
Length of utterance	502	
Sentences		374 (74.5%)
Phrases/Word combinations		65 (12.9)
Single words		38 (7.6)
Not able to do any of the above		25 (5.0)
Mode of communication (not mutually exclusive)	472	
Speech		416 (88.1)
Graphics/Symbols		48 (10.2)
Gesture/Sign		93 (19.7)
Understood by a familiar caregiver	541	
Yes		512 (94.6)
No		20 (3.7)
Don't know		9 (1.7)
Sufficient vocabulary for his/her environment	536	
Yes		430 (80.2)
No		87 (16.2)
Don't know		19 (3.5)

associated with needing SL/A services: age, gender, cerebral palsy, autism, and a psychiatric condition.

As seen in Table 5, the association between the eight functions of communication and the need for SL/A services was also examined using the chi-square statistic. It was found that the absence of any single function of communication significantly increased the likelihood of caregivers perceiving a need for SL/A services.

Of those identified as needing SL/A services (*n* = 148), 65% were not receiving services. Table 6 shows what variables were significantly related to receipt of services. Chi-squares were calculated to identify what variables were associated with receiving services. Fisher's Exact Test

Table 5

Variables Significantly Associated with Needing SL/A Services

Variable	Total Variable *n*	Needs Services No	Needs Services Yes
Down syndrome	417	9.0%	23.6%‡
Severe/profound level of mental retardation	301	6.3	21.8‡
Hearing Impairment	430	5.6	18.9‡
Not understood by a familiar caregiver	448	1.6	7.7†
Does not have sufficient vocabulary	436	3.6	43.5‡
Unable to make social contact, greet	463	2.5	14.0‡
Unable to tell own name	464	3.4	23.4‡
Unable to regulate others actions	459	5.4	32.9‡
Unable to request needs and wants	461	3.8	16.8‡
Unable to express feelings	445	4.5	17.6‡
Unable to answer questions	454	5.1	32.2‡
Unable to respond to instructions	454	0.3	7.1‡
Unable to ask questions	459	5.4	31.3‡

Note: Pearson chi-square or Fisher's Exact Test when 25% of the cells had expected counts less than 5; $^{\dagger}p < .01$; $^{\ddagger}p < .001$.

was computed when there were one or more cells with an expected count of less than 5. The only participant characteristic significantly associated with receiving services was a level of mental retardation in the severe or profound range, $p < .02$. Participant variables examined that were not found to be associated with receiving services were: age, gender, Down syndrome, cerebral palsy, autism, psychiatric illness, a hearing impairment, being understood by a familiar caregiver and having sufficient vocabulary for his/her environment.

Table 6 also shows the communication problems significantly related to receipt of service. Chi-squares and Fisher's Exact Test (where appropriate) were computed. The inability to perform four functions of communication was significantly associated with receiving services: tell their own name, $\chi^2 = 12.44$, $p < .001$; express feelings, $\chi^2 = 8.12$, $p < .01$;

Table 6

Variables Significantly Associated with Receiving SL/A Services when Identified as Needing SL/A Services

	Total Variable *n*	Needs and Receives Services	
		No	Yes
Severe/profound MR	78	15.0%	44.0%[†]
Unable to tell own name	140	14.3	40.8[§]
Unable to express feelings	131	10.6	30.4[‡]
Unable to answer questions	138	25.0	46.0[†]
Unable to ask questions	139	24.7	44.0[†]

Note: Pearson chi-square or Fisher's Exact Test when 25% of the cells had expected counts less than 5; [†]$p < .02$; [‡]$p < .01$; [§]$p < .001$.

provide information to others and answer questions, $\chi^2 = 6.40$, $p < .02$; and ask questions to obtain information, $\chi^2 = 5.50$, $p < .02$.

Discussion

Twenty-seven percent of this study sample of 559 adults with developmental disabilities was identified as needing SL/A services. As the sample used in this study was composed of all adults served by two community based agencies, this represents important information for community service planners, Speech-Language Pathologists, and Audiologists working with individuals in this community. It is expected that 10% of the population without developmental disabilities will have a communication disorder. This study confirms previous findings that identify the SL/A needs of adults with developmental disabilities to be much higher than what is expected in the typically developing population (Prasher, 1995). This means that the ratio of clinicians working in this field should also be proportionately higher.

In over half of the cases reported, it was not known if adults had had a hearing test. As many individuals with developmental disabilities are at risk for hearing loss, and the risk for hearing impairment increases with age (Evenhuis, 1995), there is obviously a need for both more awareness and more audiological services for this group. In addition, the percentage of individuals identified by caregivers as having a known hearing disorder (8.5%) would appear to be uncommonly low when compared to percentages described in the literature (Prasher, 1995), suggesting that caregivers are unable to reliably identify clients who may be experiencing hearing difficulties. This finding requires further examination. Audiological services for this group should therefore include not only assessment and treatment services but an educational component as well. This educational component should teach and alert caregivers to the necessity of regular audiological services for this population, and direct the creation of a hearing management protocol for all clients with developmental disabilities of community agencies.

Variables that were associated with being identified as needing SL/A services included a level of mental retardation in the severe/profound range and Down syndrome. These findings were expected since adaptive skill deficits in the area of communication are among the defining characteristics for persons with severe mental retardation (McLean et al, 1996) and people with Down syndrome suffer from auditory disorders to a much higher degree than do persons with mental retardation due to other causes (Evenhuis, van Zanten, Brocaar, & Roerdinkholder, 1992). However, in the case of Down syndrome, it may be that the commonality of the syndrome has resulted in a higher level of awareness of sensory impairments. Other variables associated with being identified as needing SL/A services were not being understood by a familiar caregiver, not having sufficient vocabulary for his/her environment and the inability to perform any single function of communication.

Of the adults identified as needing SL/A services, 65% were not receiving such services. An adult who had a level of mental retardation in the severe to profound range and was unable to: tell his or her own name, express feelings, provide information to others or ask questions to obtain information was more likely than others to receive SL/A services. This finding suggests that these four functions of communication may be perceived by staff to be particularly important functions, important enough to warrant intervention when the adult is not able to perform them.

The question remains, however, as to why individuals who were perceived to need services were not receiving them. This is a vital question as it is a key issue with regard to provision of services. The number of Speech-Language Pathologists and Audiologists who work with adults with developmental disabilities will not likely increase unless there is a demonstrated need for such services. The primary method of demonstrating need is the size of a referral or waiting list. If a client is not referred for service then it is assumed that service is not needed. The results of this study show that awareness of need for service alone does not always result in a referral. It is possible that referrals depend on factors such as the caregiver's awareness of the range of services that are offered by a Speech-Language Pathologist, as well as the location and availability of SL/A services in each region. It may also be that the beliefs that communication strategies are important throughout the lifespan and that adult clients can benefit from such services is required before an adult is referred for service. Future studies are needed to examine these issues.

A limitation of this study is the large amount of missing data on level of mental retardation. Due to the design of the questionnaire, it is unknown whether no response meant caregivers were unsure of the level of mental retardation, or that they had simply chosen not to answer this question. This lack of response makes the data obtained on this variable questionable, and leaves in doubt the validity of comparisons made using this variable. It also has clinical implications. If the staff did not know the client's diagnosis they could not be expected to be aware of risk factors for communication difficulties, such as hearing loss. Another limitation of this study is the absence of information regarding the degree of familiarity of the staff completing the questionnaire with the client in question. For instance, information on the history and frequency of contact with the client would be useful so that the reliability of the data could be characterized.

Despite the limitations, this study provides useful information for clinical practice and a direction for future research. Future clinical applications should be directed towards the provision of adequate speech-language and audiology services to adults with developmental disabilities. In particular, the development of educational programs for caregivers that define the speech-language and hearing disorders in adults with developmental disabilities, delineate the range of services offered by Speech-Language Pathologists and Audiologists, and describe the process of referral are needed. The development of a hearing management protocol for agencies of community living to help identify individuals at risk and to ensure timely screening and good management of hearing needs is also recommended. Future research should be aimed at the evaluation of such interventions.

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A Rose is a Rose: Effects of Label Change, Education, and Sex on Attitudes Toward Mental Disabilities

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Previous research on attitudes toward mental disabilities has shown a consistent, positive effect when accurate information regarding mental disabilities (i.e., education) is made available. Conversely, the effects of labelling and sex differences produced inconsistent results. This study approaches such attitudes in terms of the "cognitive miser" conception of schema use and examines whether changing labels applied to disabilities alters attitudes toward an individual with a disability. We examined the attitudes held by 168 university/college students employing a test-treatment-retest design. The pretest involved completing the Mental Retardation Attitude Inventory-Revised (MRAI-R). Then participants read an educational vignette emphasizing the skills and daily activities of a person with a mental disability, either mental retardation (MR) or attention deficit disorder (ADD). In approximately half the cases a novel label for the mental disability was presented. The retest again employed the MRAI-R, modified to reflect the novel label where necessary. Two 2 × 2 × 2 split plot ANOVA with factors sex of subject (male vs. female), label change (yes vs. no), and education (pretest vs. posttest) were used. Results showed main effects for sex and education, but the effects of label change and all interactions were nonsignificant. Results indicated that, for both disabilities, females tend to hold more positive attitudes and that education about disabilities can improve attitudes regardless of whether a new or old label is applied to the disability.

When scoliosis forced Laughie [pronounced Lockee] Rutt into a wheelchair at 15, he was called a cripple. When he graduated from Acadia University in 1977, he was called physically disabled or handicapped. When he got married in 1981, he was called mobility challenged or physically impaired. Today, in the politically correct '90s, he is "a person with a disability." Sitting in his downtown Halifax office, sipping tea and swapping jokes with his colleagues, the slight Cape Bretoner says that all he's ever wanted to be called is Laughie (Proctor, 1996, p. B1).

Even though the above illustration refers to a physical disability, similar changes in acceptable labels have also occurred with mental disabilities (Scheerenberger, 1983). One such disability that has fallen into the "cycle" (Hastings, 1994) of re-labelling old terminology is mental retardation (MR). In this study we will examine the effects of education about persons with disabilities and introducing novel labels for mental disabilities in the context of a laboratory simulation. Our theoretical perspective uses the "cognitive miser" conception of schema functioning to generate the hypothesis that changing labels is unlikely to affect attitudes toward mental disabilities. It is expected that education, in the present case, the addition of new information emphasizing the abilities a person with severe mental retardation and his/her similarity to the general public, will more likely affect the schemas and their corresponding attitudes of others. Most interesting is the possibility that the combination of label change and education will facilitate the production of a new schema which would be associated with primarily positive attitudes. However, it is also possible that existing schemas for mental disabilities will be altered to accommodate both the novel label and education. Evaluating this hypothesis is the primary purpose of the present study.

Schemas are bundles of knowledge stored in memory that represent a particular generic procedure, object, event, or social situation (Thorndyke, 1984); schemas are used to process information about social or ethnic groups (Anderson, 1980). The process of labelling people with mental disabilities involves categorizing them into groups according to their most salient characteristics based on assumptions regarding those characteristics (Fiske & Taylor, 1991). Cognitively, these characteristics or variables are arranged into a coherent cognitive structure called a schema (Crocker, Fiske, & Taylor, 1984). Schemas are used as "cognitive tools" to reduce the effort required to perform mental tasks and to facilitate the organization, structure, and interpretation of new information (Crocker et al., 1984; Macrae, Milne, & Bodenhausen, 1994). However, they may also facilitate recall of false information and events and tend to be resistant to change (Crocker et al., 1984). This property of schema structure helps to explain why inaccurate, prejudicial attitudes develop and, more importantly, why they endure regardless of the labels used.

Terminology for mental retardation has changed many times over the years. Previous terms such as “idiocy,” “feeble-mindedness,” “mental deficiency,” and “mental subnormality” gave way to more modern labels such as “mentally disabled,” “mentally handicapped,” “mentally challenged” and “developmentally disabled” (Clarke & Clarke, 1985). This “labelling cycle” (Hastings, 1994) is exemplified by a school district that placed children into a special educational program in an attempt to remove the harmful effects of labelling them as “mentally retarded” (Beirne-Smith, Patton, & Ittenbach, 1994). The program, Direct Instructional Systems for Training Arithmetic and Reading (D.I.S.T.A.R.) was publicized with the intent of decreasing the stigma associated with the mentally retarded label. Soon thereafter, negative attitudes associated with the existing label (i.e., MR) transferred to the previously meaningless acronym, in this case, D.I.S.T.A.R. Some concerned citizens pleaded that the program be terminated because they felt D.I.S.T.A.R. was a program for “dumb” kids and other children mocked the students in the program, yelling “DISTAR, DISTAR” (Beirne-Smith et al., 1994, p. 77). Even though the label changed, the underlying attitude remained. It is likely that the negative connotation may be attached to the mental representation (i.e., schema) for a condition, regardless of the specific label utilized.

The evaluative component of a schema is reflected in a person’s attitudes. The literature concerning the effects of labelling on attitudes toward MR shows inconsistent results. The majority of studies regarding labelling and MR found that a label has a weak negative effect on attitudes toward persons with MR (e.g., Sparrow, Shinkfield, & Karnilowicz, 1993). These results were more likely caused by the label interacting with such variables as academic performance (Budoff & Siperstein, 1978), behavioural aggressiveness of the target person (Gottlieb, 1975), and one's theoretical position on the conception of MR as being either a developmental delay or a basic difference in psychological functioning (Yeates & Weisz, 1985). Other studies have indicated a strong negative effect of labels (Rothlisberg, Hill, & D'Amato, 1994) but only in specific circumstances and while interacting with other variables (Gottlieb, 1975). Finally some studies showed that labelling may have no effect on attitudes (Aloia, 1975; MacMillan, Jones, & Aloia, 1974). Alternatively, there are studies that report that education about disabilities, in one form or another, has a significant positive effect on attitudes toward an individual with MR (Bak & Siperstein, 1987; Esposito & Peach, 1983; Rees, Spreen, & Harnadek, 1991; Wishart & Johnston, 1990).

Equivocal results also are seen with regard to reported sex differences in attitudes toward MR. Studies reviewed by Yuker (1988) do not consistently show sex differences on attitudes toward MR; rather sampling problems and social desirability are reported as plausible causes for observed differences. However, sex differences are found in various studies of attitudes toward MR (Bak & Siperstein, 1987; Budoff & Siperstein, 1978; Fiedler & Simpson, 1987; and Sparrow et al., 1993). As well, Gilligan's *In a Different Voice* (1982) provides an adequate explanation of why there may be such differences. Gilligan's theory of gender socialization states that females and males are socialized to express different moral orientations that might be evident in responses to attitude scales. Given the inconsistent findings regarding sex differences in attitudes towards MR, sex of the rater was included as an independent variable in this study.

The purpose of this study was to examine the effects on attitudes of two variables: (1) changing the labels used to refer to particular mental disabilities, and (2) education designed to demonstrate the similarities between a specific individual with a mental disability and that of an average person. In addition to MR, attention deficit disorder (ADD) was also studied to test whether the labelling phenomenon under investigation applies to other disabilities and disorders. As in previous studies (e.g., Rothlisberg et al., 1994), education was provided by using a vignette describing the daily activities of a hypothetical person. Education has consistently been shown to have a positive influence on attitudes, but the labelling controversy continues. Interactions have been cited indicating that the label may have the greatest effect when combined with other variables, such as behavioural aggressiveness of a labelled person (Gottlieb, 1975). We believe that variable interactions (in this case, label × education) create a new property that is not simply additive in nature and thus demonstrates an effect that would not be observed by itself. Therefore, it is hypothesized that (1) a new label will have little or no effect on attitudes, (2) education will lead to a positive change in attitudes and (3) the combination of a new label and education concerning this new label will generate the most favourable attitudes toward individuals with MR and ADD. We also examined possible sex differences. The methodological approach for the present study was borrowed from experimental social psychology and the process was simulated under controlled laboratory conditions.

Method

Participants

The participants were 168 students from a small University College who were recruited from academic, technology, and trade programs. Participants were 92 males and 76 females; mean age was 21.8 years (SD = 4.8).

Recruitment

Instructors of various courses, selected at random from the University College's timetable, were contacted and the study was described to them. Permission was obtained from the instructors to recruit participants from their class. Upon arriving at the testing room, participants were administered one of four versions of the questionnaire booklet. To ensure similar sample sizes for each of the four versions of the questionnaire, the booklets were distributed consecutively (Version 1 through 4) with the first one chosen at random. Informed consent was obtained on the first page of the questionnaire and participating classes received debriefing feedback sheets following completion of data collection.

Materials

Attitude test. Antonak and Harth's (1994) *Mental Retardation Attitude Inventory-Revised* (MRAI-R) which was used for all attitude assessments. The MRAI-R inventory contains 29 items and includes subscales called Integration-Segregation, Social Distance, Private Rights, and Subtle Derogatory Beliefs. It has been reported that the MRAI-R adequately controls for social desirability responding and has been shown to be a valid and reliable instrument (Antonak & Harth, 1994).

Educational materials. The educational vignette used to describe and label a hypothetical person with a mental disability was based on a description of a severely mentally retarded individual provided by Beirne-Smith et al. (1994). The vignette described daily life activities, hobbies, and interests of a person with severe MR. Four versions of the vignette were written to be identical across groups, except for slight grammatical alterations to introduce different labels. The person was described as having mental retardation (Group 1), Zahn-Waxler Syndrome (Group 2), attention deficit disorder (Group 3), or Thivierge Syndrome (Group 4). In Group 2, Zahn-Waxler Syndrome was introduced explicitly as a term replacing mental retardation. In Group 4, Thivierge Syndrome was introduced explicitly as a term replacing attention deficit disorder. Each of the new labels was presented five times within the vignette in an effort to enhance usage of the new terminology. Whereas prior studies have compared existing labels (e.g., "mental disability" and "mental handicap"), the present study used novel labels to examine associations between new and existing labels.

Design

A 2 × 2 × 2 split plot ANOVA with factors, sex of the participant (male vs. female), label change (yes vs. no), and education (pretest vs. posttest) was used. The study was composed of three main parts: an attitude pretest, an educational vignette that emphasized the abilities of a person with a mental disability, and an attitude posttest. All participants received the same 58-item pretest questionnaire that included 29 MRAI-R items assessing attitudes toward MR and the same 29 MRAI-R items revised to assess attitudes toward ADD. The 58-items were presented in a random order.

Procedure

First, the participants filled out the MRAI-R. Then they read one of four educational vignettes (see Appendix) describing a person named "Marty" (taken from Beirne-Smith et al., 1994) that emphasized his abilities (e.g., he held a job, enjoyed sports, and lived in an apartment with roommates). The label referring to Marty was the only the difference among the vignettes. Participants in Group 1 (*n* = 44) were told that Marty was mentally retarded. Group 2 (*n* = 43) was told that Marty was mentally retarded but that there was a new term for the condition, "Zahn-Waxler Syndrome." Group 3 (*n* = 39) was told that Marty had attention deficit disorder. Group 4 (*n* = 42) was told that Marty had attention deficit disorder but that there was a new term for the condition called "Thivierge Syndrome." The posttest was then presented. For all participants, the posttest was comprised of a 29-item attitude scale (MRAI-R) which was worded to suit the label used in the vignette. Demographic questions (age, gender, university or college program, and education) followed the posttest.

Immediately following the vignette, preceding the posttest, participants completed a five-item, open-ended comprehension test. Three of the items questioned story content. A fourth item asked, "What condition does Marty have?" For groups 2 and 4, a fifth item asked, "What was the previous name for Marty's condition?" Correctly responding to both these questions verified the label change. Only one participant had two incorrect responses that resulted in discarding his or her data.

Results

Before considering the main results of the study, it was necessary to examine the reliability of the MRAI-R, especially when worded to refer to ADD. First we examined the consistency of the responses to the items for the two conditions. To do this, scores for each item referring to MR were correlated with the same item worded to refer to ADD. The minimum item-item correlation was $r = .23$ and the median correlation was $r = .50$, indicating consistency between scores for MR and ADD. Next, we examined the internal consistency of the MRAI-R using Chronbach's alpha. For pretest scores, the reliabilities were comparable (ADD = .89 and MR = .90) and replicated Antonak and Harth's (1994) findings. These results indicate that the scale produces reliable scores when worded to refer to MR or ADD.

Two, 2 × 2 × 2 split plot ANOVAs with factors sex of the participant (male vs. female), label change (yes vs. no), and education (pretest vs. posttest) were performed. One ANOVA tested attitudes relating to mental retardation, while the other examined ADD. Analysis of the data for the MR groups (Groups 1 and 2) demonstrated main effects for education, $F(1,70) = 8.83$, $p < .01$ and sex, $F(1,70) = 5.37$, $p < .05$; there was no significant main effect for label change or interaction. The ANOVA for the ADD groups (Groups 3 and 4) also demonstrated main effects for education, $F(1,70) = 20.10$, $p < .01$ and sex, $F(1,70) = 10.34$, $\mathrm{p} < .01$. Again, there was no significant main effect for label change or any interaction. Effect size estimates (eta-squared) showed that education produced the strongest effects, and that the effects of both education and sex were stronger for ADD than for MR. The overall tendency was for females to have more positive attitudes than males, and for attitudes to be more positive on the posttest than on the pretest.

Finally, two planned comparisons (*t*-tests) were conducted to test for possible labelling effects on posttest attitude scores. There was no significant difference in attitude between the new label "Zahn-Waxler Syndrome" and the old label "Mental Retardation," $t(75) = 1.00$, $p > .05$, or between the new label "Thivierge Syndrome" and the old label of "attention deficit disorder, " $t(74) = .46$, $p > .05$. Figures 1 and 2 illustrate the similarity between attitude scores for the new and old labels.

Discussion

This investigation demonstrated that even very brief information about the capabilities of persons with MR can result in more positive attitudes. The findings also suggest that changing the label assigned to a mental disability, such as MR or ADD, will itself not improve attitudes. Furthermore, no support was found for an interaction between a new label and education. Additional results show sex differences, with females possessing generally more positive attitudes toward both MR and ADD than males. Finally, the current study demonstrates that the MRAI-R can be adapted successfully to refer to other mental disabilities, specifically ADD.

Providing education through vignettes that demonstrate the similarities between an individual with a mental disability and an average person appears to create improvement in positive attitudes toward both MR and ADD. This is consistent with the results reported by Yeates & Weisz (1985). Education in one form or another has been demonstrated to improve attitudes toward MR (Bak & Siperstein, 1987; Esposito & Peach, 1983; Rees et al., 1991; Wishart & Johnston, 1990). This result may be explained by the process that occurs when schemas change. The cognitive structure of a schema is comprised of several variables that may be changed when a schema is activated. These variables can be modified as new information is learned and ultimately alter the structure of a schema (Crocker et al., 1984). As participants in this study read the vignettes, their schemas for MR or ADD were activated. This opened the existing schema structure to possible alteration in order to

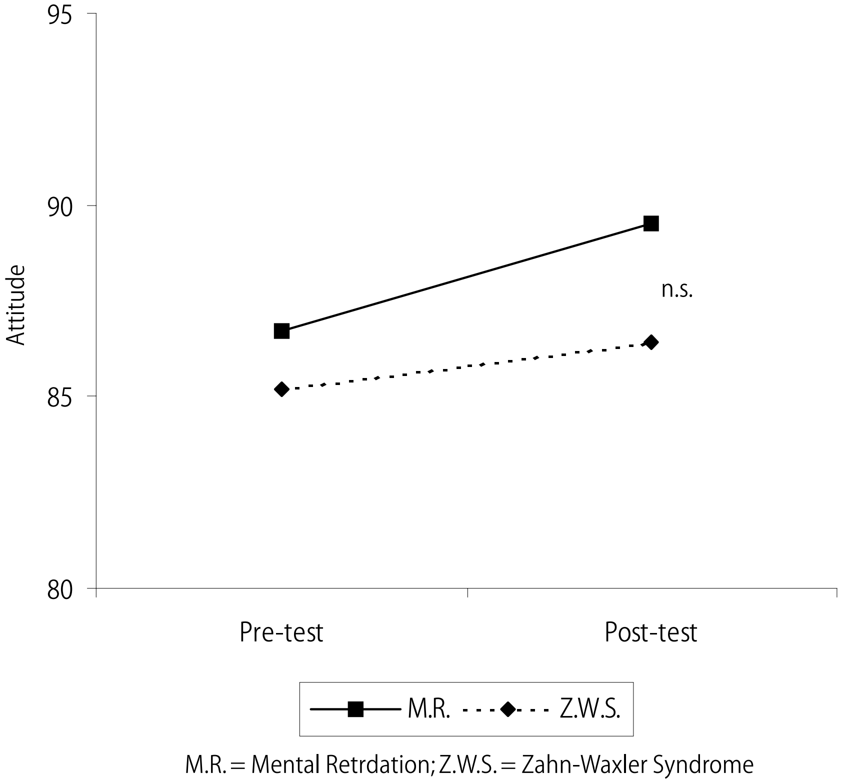
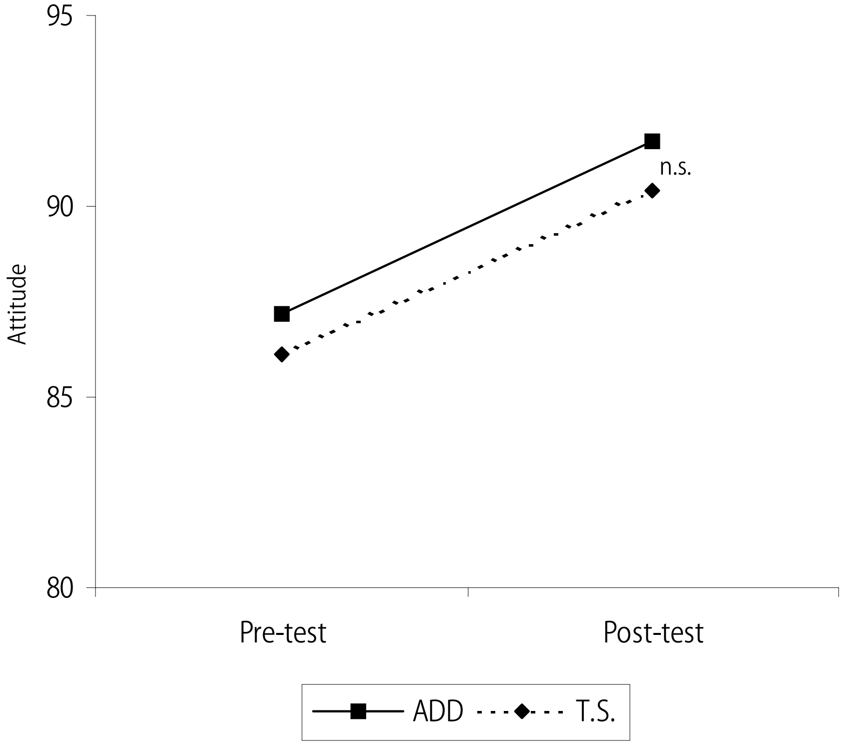


Figure 1
Effects of education and labelling on attitudes toward mental retardation

accommodate new information (i.e., the capabilities of the individual described in the vignette). Less cognitive work would be required to modify an existing schema for MR or ADD than would be required to create an entirely new schema.

The present results do not support the notion that changing labels for mental disabilities has an effect on attitudes. Whereas one must be cautious in interpreting nonsignificant results, the stability in attitudes can be addressed. If we are "cognitive misers" and resist extra mental activity, as social-cognitive research suggests (Fiske & Taylor, 1991), then it is likely that participants simply employed their existing schema for MR when presented with the new label, Zahn-Waxler Syndrome.



ADD = Attention Deficit Disorder; T.S. = Thivierge Syndrome

Figure 2
Effects of education and labelling on attitudes toward attention deficit disorder

Similarly the label applied to the schema for ADD might change to Thivierge Syndrome; however, the basic structure of the schema remains intact. In order to save cognitive energy (Macrae et al., 1994), new labels become directly associated with old labels. This also explains why new labels, even with their more positive connotations, so quickly become regarded negatively (Hastings, 1994).

The expected interaction between education and labelling was not supported by the data. This result was particularly interesting because it was hypothesized that this interaction would create the most positive attitudes. It was believed that a new schema might be created for the labels Zahn-Waxler Syndrome and Thivierge Syndrome because new information (i.e., education) was associated with these novel labels. The reason for the non-significant interaction may be explained by the possibility that, in this case, less cognitive energy was required to replace the schema label than to create a new, distinct schema. The new information provided in the vignette could be assimilated into the existing schema, leading to more positive attitudes. This result mirrors the pattern of results obtained in previous research using authentic, community-based interventions and helps explain the futility of the "labelling cycle" (Hastings, 1994).

It was found that female participants responded with more positive attitudes than male participants. Previous studies of attitudes toward mental disabilities have shown similar gender differences (Bak & Siperstein, 1987; Budoff & Siperstein, 1978; Fiedler & Simpson, 1987; and Sparrow et al., 1993; however, see critiques of studies of gender differences by Yuker, 1988; and Jones, 1984). These differences may be explained by applying Gilligan's (1982) theory of gender socialization which states that females and males are socialized to express different moral orientations. In comparison to males, females are more often taught to nurture others and, therefore, are more likely to express sensitivity and empathy as exemplified in their responses to the attitude scales about persons with disabilities.

Although the present results can be adequately explained using the theories discussed above, the experimental design used here is open to other interpretations. Using a pretest-posttest design allows for the possibility of "testing" effects or demand characteristics (Myers & Hansen, 1997). Testing effect refers to the phenomenon that taking a test on more than one occasion tends to produce better scores on subsequent tests. This might explain the increase in attitudes observed in the present study. However, for approximately half of the participants, the items were changed to incorporate the novel label with virtually no effect on the difference in attitude scores. As for demand characteristics, it is possible that participants felt that they must provide more positive attitudes after reading the educational vignette. We suspect that those given the novel label might have been under even greater demand to show improvement in their attitudes. If this were true we would expect an interaction between labelling and education, but this did not occur. These potential problems cannot be ruled out completely and readers should be aware of potential alternate interpretations. It also should be noted that this study was a highly controlled, laboratory-based experiment and it is not intended to be a test of the effects of a large scale intervention such as an education program.

The results of this and other studies suggest that changing labels may not be a productive way to reduce stigma associated with various labels for MR. MacMillan et al. (1974) cautioned that research outcomes are not attributable "… to any one independent variable such as the label" (p. 251) and keep in mind the "complexity of the labelling phenomena" (p. 252). The present study provides one more piece of evidence that suggests it is of questionable utility to re-invent labels and expect a significant improvement in attitudes. Historically, it appears that the stigma associated with labels (e.g., MR and ADD) does not disappear simply by changing the offensive labels. The stigma appears to be closely associated with the schema for the condition. When individuals are presented with a new label for a mental disability, they continue to employ their existing schema for that disability and can simply change the name of the schema. The stigma associated with mental disabilities endures because schemas facilitate recall of both correct and incorrect information consistent with the schema and this resists change. However, in spite of this, attitudes toward mental disabilities in the community have improved over time (Rees et al., 1991). As these findings and others (Bak & Siperstein, 1987; Esposito & Peach, 1983; Wishart & Johnston, 1990) indicate, this improvement may be more likely the result of education and exposure which has modified peoples' schemas to some extent rather than changing labels. Therefore, it is recommended that effort should be invested in educating people about disabilities, instead of confusing them with new terminology.

The results of this study may have practical implications. It has been found that attitudes can be made more positive by introducing positive information (i.e., the capabilities of a labelled person) into an individual's schema. Clinicians might assess the parents' knowledge of relevant disabilities (e.g., mental retardation) and provide accurate information which emphasizes positive qualities and characteristics of these conditions. This effort theoretically would alter the parents' schema, thus producing more favourable attitudes towards their children who have disabilities. Similar efforts could be made by curriculum designers and educators in the school system.

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Appendix: Example of a Vignette

For those who have not had the opportunity to know individuals with severe or profound mental disabilities, the mere thought of these conditions conjures up thoughts of state hospital wards or county homes filled with low-functioning people who sit motionless, or wander aimlessly around white-walled rooms with little to do. Although these nightmarish settings do exist in some parts of the world, persons with severe or profound disabilities can be viable members of today's society. The pictures mentioned above come, in the majority of situations, only from bad dreams or from memories of bygone days, when our technology and educational achievements were more primitive. In keeping with the modern approach to mental disabilities, new terms have been proposed to describe certain conditions. Recently, Zahn-Waxler syndrome has been proposed to replace mental retardation.

Marty is twenty-four years old and has a severe form of Zahn-Waxler syndrome. He shares an apartment on Sydney's North Side with two other individuals, one of whom has a disability. Marty gets up each weekday morning and assists in meal preparation, eats breakfast, and helps clean up. Although he has a severe form of Zahn-Waxler syndrome, he walks with one of his roommates to the bus stop and takes a city bus about ten miles to his place of employment – Joe's Warehouse restaurant. After arriving there at 9:30 a.m., he cleans the floor and tables and sets up each table in preparation for the restaurant's 11:30 a.m.

opening. He also stocks the work station with silverware, cups, glasses, ice, and napkins, following the picture chart of the stations' layout. He stacks the cooking area with dishes and takes a short coffee break with his coworkers. Once the lunch crowd arrives, he serves ice water to customers and buses tables, sometimes with assistance from kitchen personnel. At about 1:30 p.m. he leaves the restaurant with the lunch all employees receive (Marty's is a light one – he's watching his weight). He meets a friend for lunch in a store across the street and then he walks with his friend to his second job at Kwik Kopy Printers. There he works alongside other employees stencilling brochures, tickets, and business cards. At about 5:00 p.m. he gets a ride home from one of his coworkers who also lives on the North Side. Marty pays the driver one dollar per day for this carpool arrangement.

At home, Marty's duties vary – sometimes he sets the table, at other times he assists in meal preparation or works on cleaning up. After supper he participates in any number of activities: going to a movie or a sporting event with a friend or a roommate; playing catch or frisbee with his roommates in the common area of his apartment complex; swimming in the pool; or just being a "couch potato" when the weather is not conducive to outdoor activities. During the summer, Marty plays on Kwik Kopy's coeducational softball team and is known to drink a beer or two after the game with his teammates. Marty recently joined the YMCA with his roommates and exercises there twice a week.

With his earnings, Marty has been able to do a lot of interesting things. He attends Cape Breton Oilers hockey games, U.C.C.B. hockey and basketball games, has a great stereo, and last year took his first plane trip with one of his friends to a wilderness retreat in British Columbia in a program offered by a Canadian outdoor association. This description of Marty's daily activities (his employment, home life and extracurricular activities) is like that of many individuals. Based on Marty's abilities to be a productive member of society, it is difficult to comprehend that Marty has a severe form of Zahn-Waxler syndrome. Note, the proposal of this new term, Zahn-Waxler syndrome has been implemented in a variety of regions in North America.

Hierarchical Ordering of Auditory Discriminations and the Assessment of Basic Learning Abilities Test

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The Assessment of Basic Learning Abilities (ABLA) test assesses the ease or difficulty with which persons with developmental disabilities are able to learn a motor imitation, a position discrimination, two 2-choice visual discriminations, and two 2-choice auditory discriminations. These tasks are hierarchically ordered in level of difficulty and are predictive of other task performance. We expanded the ABLA to include four additional auditory discriminations and examined the hierarchical ordering of the new discriminations. Our results with 25 participants with developmental disabilities, and in combination with the results from three previous studies, showed reliable and consistent relations among three of the auditory discriminations and the ABLA test. Limitations and practical implications of the findings are discussed.

Persons with severe developmental disabilities frequently face difficulty in mastering important everyday tasks. Evidence suggests that this difficulty is related to a lack of basic discrimination skills. Kerr, Meyerson, and Flora (1977) examined common training tasks presented to persons with developmental disabilities in areas of self-care, educational, and vocational tasks. They determined that most tasks required an ability to learn to imitate, and to master one or more of five two-choice discriminations. Kerr et al. developed a test, called the Assessment of Basic Learning Abilities (ABLA) (formerly referred to as the Auditory Visual Combined Discrimination test), to assess an individual's ability to learn such discriminations. The ABLA test includes an imitation task, a 2-choice position discrimination task, two 2-choice visual discrimination tasks, and two 2-choice auditory discrimination tasks. Table 1 shows the ABLA test Levels and some everyday tasks at each level.

When testing a student at a particular ABLA level, the student is given a demonstration, a guided trial, and an opportunity for an independent response. The student then is given a series of test trials at that level. Correct responses are praised (and occasionally reinforced with an edible), and incorrect responses are followed by an error correction procedure. Training continues at a level until the student reaches a passing criterion of eight consecutive correct responses, or a failure criterion of eight cumulative errors.

Several characteristics of the ABLA test have been well researched. First, the ABLA tasks are hierarchically ordered in difficulty from level 1 (imitation) to level 6 (auditory-visual discrimination) (Kerr et al., 1977; Martin, Yu, Quinn, & Patterson, 1983; Wacker, Steil, & Greenebaum, 1983). Second, failed ABLA tasks are difficult to teach with commonly-used prompting and reinforcement procedures (Meyerson, 1977; Stubbings & Martin, 1995, 1998; Witt & Wacker, 1981; Yu & Martin, 1986). Mastery, if attained at all, often requires hundreds of teaching

Table 1

ABLA Test Levels and Some Everyday Tasks at Each Level

ABLA Levels and Original Names	ABLA Test Task and Everyday Examples
Level 1 Imitation	The tester puts an object into a container and asks the student to do likewise. • Children playing follow-the-leader • Taking turns stirring cake batter
Level 2 Position Discrimination	When a red box and a yellow can are presented in a fixed position, the student is required to place a piece of green foam in the container on the left when the tester says, "Put it in." • Turning on the cold (vs. the hot) water tap • Placing a fork on the left side of a plate when setting a table

Table 1 (cont'd)

ABLA Test Levels and Some Everyday Tasks at Each Level

ABLA Levels and Original Names	ABLA Test Task and Everyday Examples
Level 3 Visual Discrimination	When a red box and a yellow can are randomly presented in left-right positions, the student is required to place a piece of foam in the yellow can when the tester says, "Put it in." • Locating own printed name on the blackboard • Finding a particular shirt in a closet when the location changes each time it is replaced
Level 4 Match-to-Sample	The red box and a yellow can are randomly presented in left-right positions and the student is given either a yellow cylinder or a red cube. The client is required to place the yellow cylinder in the yellow can and the red cube in the red box. • Sorting socks into pairs • Restocking a partially emptied salad bar
Level 5 Auditory Discrimination	When presented with a yellow can and a red box in fixed positions, the student is required to put a piece of green foam in the appropriate container when the tester randomly says, "red box" or "yellow can." • Responding appropriately to the spoken words, "stop" and "go" • Responding to request such as "Stand up" vs. "Sit down"
Level 6 Auditory-Visual Combined Discrimination	The same as level 5, except that the right-left position of the containers is randomly alternated • Responding to instructions about objects or people when their positions frequently change (e.g., "Please stand beside Tom")

trials. Third, the ABLA test has demonstrated high test-retest reliability (Martin et al., 1983). Fourth, the ABLA test results are predictive of a person's performance on other tasks including academic and vocational skills (Martin et al., 1983; Meyerson, 1977; Stubbings & Martin, 1995, 1998; Tharinger, Schallert, & Kerr, 1977; Wacker, 1981). Lastly, predictions of students' performance on various training tasks based on their ABLA test results were significantly more accurate than predictions by experienced teachers who had worked with those students for a minimum of eight months (Stubbings & Martin, 1998).

The ABLA is a valuable assessment tool for training for several reasons (Yu, Martin, & Williams, 1989). First, because an individual can learn new tasks more quickly if the required discriminations are in their repertoire, the ABLA test can be used for selecting and sequencing training tasks in an order optimal for learning. Second, the ABLA test can be used to identify teaching prompts that are matched to the learner's abilities. Prompts that require discriminations that are not in the learner's repertoire are likely to be ineffective. For someone who passed up to level 3 (visual discrimination) but failed higher levels (visual matching-to-sample and auditory discriminations) on the ABLA, modeling and visual prompts should be more effective than auditory cues or a matching-to-sample procedure. Third, in expanding a person's discrimination skills, targeting the first failed ABLA level for training may be an efficient method for developing the prerequisite skills needed for more complex discriminations.

Two lines of evidence suggest that it may be worthwhile to examine the relationship between the ABLA auditory tasks and other types of auditory discriminations. First, the ability to pass the ABLA auditory tasks may be a prerequisite to learning more complex language discriminations. Forty-two typically developing children (13 to 35 months old) who were able to pass the two auditory discrimination tasks of the ABLA had significantly higher scores on mean length of utterance, upper bound, and vocabulary sample than age-matched children who failed those two auditory tasks (Casey & Kerr, 1977). More recently, Ward

(1995) found that children with autistic-spectrum syndrome also exhibited the same hierarchical relationship in their ABLA performance. Moreover, the children's expressive communication abilities were highly correlated with their ABLA performance: Ward found that only the children who had achieved ABLA visual matching used single words or signs, and only the children who had acquired the auditory tasks of the ABLA produced two or three-word utterances.

Second, research indicates that language comprehension, as represented by failed ABLA auditory discriminations, is extremely difficult to teach using standard prompting and reinforcement procedures (Meyerson, 1977; Witt & Wacker, 1981). In addition to using effective prompt-fading and reinforcement procedures, language comprehension might be taught more efficiently if additional discriminations could be identified as intermediate steps for training (Walker, Lin, & Martin, 1994; Ward, 1995). For example, Meyerson noted that "[the ABLA auditory-visual discrimination] does not encompass all possible auditory discriminations that can be made" and "… children who failed [ABLA level 6] made some kinds of auditory discriminations" (p. 119). For example, a child who failed the ABLA auditory tasks may respond successfully to other familiar sounds (e.g., his/her name being called).

Several auditory discriminations have been examined in previous research. One type of auditory discrimination involves hearing a non-speech sound, and then responding on an apparatus to produce the same sound. Walker et al. (1994) developed a procedure to assess clients' ability to match simple sounds. A bell and a tambourine are placed on a table in front of the client, a second bell and tambourine are hidden from view. When one of the sounds is presented repeatedly using the hidden objects, the correct response by the client is to manipulate one of the objects on the table to produce a matching sound. This is an auditory-visual nonidentity discrimination in that the client hears a particular (non-speech) sound which is presented repeatedly, visually discriminates and then manipulates the apparatus that produces a matching sound. This discrimination was also examined by Ward (1995) using different task materials (a cylinder and a cube that produced different sounds when shaken). Preliminary evidence indicates that this task falls between levels 4 (match-to-sample) and 5 (auditory discrimination) on the ABLA test in terms of difficulty. A second type of assessment evaluates a client's ability to hear a speech sound, and then to manipulate an object to consistently produce a non-matching sound. This task is similar to the above, except that the tester vocally simulated the sound as the cue for responding. In Ward's study, for example, when the tester said, "squeak-squeak-squeak" repeatedly, the client was required to shake the cylinder which producing the squeaking sound. When tester said, "ch-ch-ch," the client was required to shake the cube filled with rice. This also is an auditory-visual nonidentity discrimination, but one that involves presenting a speech sound repeatedly as the auditory cue. Ward's results suggests that it may be less difficult than ABLA level 6 (auditory-visual combined discrimination).

Another type of auditory discrimination involves the student hearing three speech sounds that are presented successively, two of which are identical (or very similar), and then indicating which of the two sounds are identical. Preliminary evidence suggests that this type of auditory-auditory identity discrimination may be more difficult than ABLA level 6 (Barker-Collo, 1995; Lin, Martin, & Collo, 1995). A fourth type of auditory discrimination involves recognizing that two speech sounds that are presented successively go together, even though they are different (i.e., an auditory-auditory nonidentity discrimination). For example, if one person says, "ice," a second person says, "rink," and a third person says, "ball," the task is to recognize that "ice" and "rink" are a match.

The four discriminations described above represent a range of auditory discriminations that (1) require different skills, (2) may be hierarchically sequenced, (3) may provide intermediate steps for training, and (4) could refine the acuity of the ABLA test. Research is needed to confirm their relationships with the ABLA and each other. The present research examined this possibility.

Method

Participants and Setting

The participants were 25 individuals (16 males, 9 females) who were receiving services from St. Amant Centre, a residential and community resource centre for people with developmental disabilities. Eighteen participants resided at the Centre, five lived in group homes operated by the Centre, and two lived with their families. The participants' characteristics are presented in Table 2. All sessions were conducted in a session room at the St. Amant Centre or in a quiet area in the participant's home.

Test Materials

Materials used in the ABLA tests included a yellow can (15 cm in diameter × 17 cm in height), a red box with black stripes (14 cm × 14 cm × 10 cm), an asymmetrical piece of green foam (5 cm in diameter), a wooden yellow cylinder (2.5 cm × 6 cm), and a wooden red cube with black stripes (4 cm × 4 cm). For three of the four auditory matching tasks, the materials included: (1) two identical tambourines and two identical bells for a two-choice task to produce a matching sound; (2) a rattle and a can filled with rice for a two-choice task to produce a nonmatching sound; and (3) a blue pen and a red block with black stripes for an auditory-auditory identity matching task. There were no materials needed for an auditory-auditory nonidentity matching task.

Testing Procedures

ABLA Test. Baseline assessments were conducted on the ABLA using the procedures developed by Kerr et al. (1977). Because we anticipated that the auditory discriminations would be above (more difficult than) ABLA level 4, a participant was required to pass at least the first four levels of the ABLA in order to be included in the study. In the present sample, six participants passed the first four ABLA levels (and failed

Table 2
Characteristics of Participants

	Sex	Age (years)	Diagnosis	Level of Functioning
1	M	21	Fetal Alcohol Syndrome with Microcephaly/Mental Retardation	Severe*
2	M	25	Mental Retardation	Severe*
3	F	27	Unidentified Genetic Disorder	Severe
4	M	22	Unknown	Severe*
5	M	40	Unknown	Moderate
6	F	31	Unknown	Profound
7	M	29	Unknown	Severe to Moderate
8	F	28	Multiple Congenital Abnormalities	Moderate
9	M	19	Mental Retardation	Severe*
10	M	23	Down Syndrome	Severe*
11	M	29	Down Syndrome	Severe*
12	M	39	Multiplex Congenital	Moderate
13	M	30	Lesch-Nyhan Syndrome	Moderate
14	F	6	Autism	Severe*
15	M	36	Unknown	Mild to Moderate
16	F	28	Autistic Syndrome	Severe
17	F	41	Unknown	Moderate
18	F	32	Unknown	Severe*
19	M	42	Unknown	Severe
20	M	10	Down Syndrome	Severe*
21	M	35	Unknown	Mild
22	F	41	Unknown	Mild
23	F	34	Unknown	Moderate to Severe
24	M	29	Down Syndrome	Severe*
25	M	30	Microcephaly	Mild

* Based on Scales of Independent Behavior (Bruininks, Woodcock, Weatherman, & Hill, 1984).

levels 5 and 6), and the remainder passed all six ABLA levels.

A Two-Choice Task to Produce a Matching Sound. The assessment procedures were the same as those described by Walker et al. (1994). During testing, the participant sat across the table from the tester. A tambourine and a bell were placed about 30 cm apart on the table, in front of the participant. Another bell and tambourine were placed under the table out of the participant's view.

A pretest routine, which consisted of a demonstration, a guided trial, and a practice trial, was carried out before testing began. The demonstration trial was provided by the tester who hit the hidden bell consistently for 10 seconds and said, "make the same sound." The tester then hit the comparison bell on the table to match the sound. In the guided trial, the tester hit the hidden bell and requested the participant to "make the same sound." The tester then guided the participant's hand to hit the comparison bell on the table. In the practice trial, the tester hit the hidden bell repeatedly, requested the participant to "make the same sound," and waited for the participant to respond independently. The pretest routine was repeated if an independent correct response did not occur during the practice trial. If an independent correct response occurred on the practice trial, the pretest routine was repeated using the tambourine. Testing and scoring began only after the participant performed a correct response on the practice trial with the bell, and then with the tambourine. During the pretest routine and testing, participants were praised following every correct response and were given a small amount of preferred edibles (e.g., potato chips), on average, after every four correct responses to motivate and maintain responding during the assessment.

On test trials, a response was scored as correct if the participant hit the correct comparison object and made the same sound. A response was scored as incorrect if the participant selected the incorrect comparison. If the participant did not respond during a trial or behaved in other ways, the tester removed the materials from the table, paused for about

10 seconds, and then repeated the trial. Nonresponding was not scored. If an incorrect comparison was chosen, the tester conducted an error correction procedure that included a demonstration, a guided trial, and a practice trial (similar to the pretest routine described above). The participant had to perform a correct response independently on the practice trial before a new test trial would be presented. Errors on correction practice trials were counted towards the failing criterion, but correct responses on correction trials were not counted towards the passing criterion. As described by Kerr et al. (1977) for the ABLA test, the passing criterion was eight consecutive correct test trials and the failing criterion was eight cumulative incorrect responses. Testing continued until the participant had either passed or failed the task.

A Two-Choice Task to Produce a Nonmatching Sound. The assessment procedure used for the two-choice task to produce a nonmatching sound was the same as that described by Ward (1995). On each trial the tester placed a rattle and a can of rice in front of the participant about 30 cm apart. The auditory cue was either “rattle-rattle-rattle” or “ch-ch-ch” spoken repeatedly by the tester. A correct response was scored if the participant picked and shook the rattle when the tester said, “rattle-rattle-rattle,” or the can of rice when the tester said, “ch-ch-ch.” A response was scored as incorrect if the participant selected the object that did not match the auditory cue given by the tester. One participant had difficulty picking up the object due to physical limitations. Therefore, the definitions of correct/incorrect responses were modified for this individual to touching or pointing to the object. The pretest routine, reinforcement and correction procedures, and the passing and failing criteria were the same as those described for the two-choice task to produce a matching sound.

Auditory-Auditory Identity Matching (AAIM). The testing procedure used for AAIM was the same as that described by Lin et al. (1995). During the assessment, the tester was positioned next to the participant. Two assistants were seated across the table with their hands extended and palms facing up. On some trials, the tester presented a blue pen to the participant and said, “pen, pen, pen” in a high rapid tone. On other trials, a red block with black stripes was given to the participant and the tester spoke in a slow deep tone, “b-l-o-c-k, b-l-o-c-k, b-l-o-c-k”. The two auditory cues were alternated randomly across trials. After the auditory cue was presented by the tester, one assistant would imitate the tester by saying, “pen, pen, pen” and the other would say, “b-l-o-c-k, b-l-o-c-k, b-l-o-c-k”. Placing the pen or block in the hand of the assistant who had said the same word as the tester was considered correct, while placing it in the hand of the other assistant was incorrect. Across trials, the two assistants randomly alternated as to who would present the matching word and who would speak first. Again, the pretest routine, reinforcement schedules, correction procedures, and passing and failing criteria were the same as that described for the two previous tasks.

Auditory-Auditory Nonidentity Matching (AANM). During the assessment, the tester sat next to the participant and two assistants sat across the table from the participant, similar to the AAIM task above. On some trials the tester would say, “ball, ball, ball” rapidly and in a high tone. On other trials, the tester would say, “i-c-e, i-c-e, i-c-e” in a slow deep tone. After the tester had presented the sample cue, one assistant would say, “field, field, field” in a high rapid tone, and the other assistant would say, “r-i-n-k, r-i-n-k, r-i-n-k” in a slow deep tone. The correct response was to point to the assistant who spoke the second word associated with the first word spoken by the tester (ball-field and ice-rink). Across trials, the sample cue was randomly alternated by the tester, and the two assistants randomly alternated as to who would present the matching word and who would speak first. The pretest routine, reinforcement schedules, correction procedures, and passing and failing criteria were the same as those described for the other three tasks.

Reliability Assessments. Interobserver reliability checks were conducted for all participants. During reliability checks, an observer independently recorded the participant’s response on each trial. An agreement was counted if both the tester and the observer recorded the same response (either correct or incorrect), and a disagreement was counted if the tester and the observer recorded different responses. Percentage agreement was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100% (Martin & Pear, 1996). Reliability checks were conducted for 80% of the ABLA baseline sessions and the mean agreement was 97%, ranging from 86% to 100%. Reliability checks were conducted for 89% of the auditory matching sessions, and the mean percentage agreement was 95%, ranging from 82% to 100%. There was 100% agreement on whether the pass or fail criterion was met on the ABLA test and on each auditory task.

For procedural reliability assessment, the tester and an observer recorded during testing whether procedures were carried out correctly using a 7-item procedural checklist. The checklist covered task set up, demonstration trial, guided trial, practice trial, auditory cues, praise for correct responses, and error correction procedure. Procedural reliability was calculated as described above for interobserver reliability. The assessments were conducted for 28% of the ABLA baseline sessions, with a mean agreement of 94%, ranging from 84% to 100%, and for 56% of the auditory matching sessions, with a mean of 90%, ranging from 56% to 100%. Only 10% of the sessions had procedural reliability below 80%.

Results

Test results of clients on the ABLA tasks and the four types of auditory matching tasks are presented in Table 3. Table 3 shows that the four auditory matching tasks and ABLA levels 4 and 6 appear to be ordered, in increasing difficulty as follows: ABLA level 4, 2-choice task to produce a matching sound, ABLA level 6, 2-choice task to produce a nonmatching sound, auditory-auditory identity matching, and auditory-auditory nonidentity matching.

Table 3

Test Results on the ABLA Tasks and the Auditory Matching Tasks

	Baseline ABLA Level 4	2-Choice Matching Sound	Baseline ABLA Level 6	2-Choice Nonmatching Sound	AAIM	AANM
1	Passed	Failed	Failed	Failed	Failed	Failed
2	Passed	Failed	Failed	Failed	Failed	Failed
3	Passed	Failed	Failed	Failed	Failed	Failed
4	Passed	Failed	Failed	Failed	Failed	Failed
5	Passed	Failed	Failed	Failed	Failed	Failed
6	Passed	Passed	Failed	Failed	Failed	Failed
7	Passed	Passed	Passed	Failed	Failed	Failed
8	Passed	Passed	Passed	Failed	Failed	Failed
9	Passed	Passed	Passed	Failed	Failed	Failed
10	Passed	Passed	Passed	Passed	Failed	Failed
11	Passed	Passed	Passed	Passed	Failed	Failed
12	Passed	Passed	Passed	Passed	Failed	Failed
13	Passed	Passed	Passed	Passed	Failed	Failed
14	Passed	Passed	Passed	Passed	Failed	Failed
15	Passed	Passed	Passed	Passed	Failed	Failed
16	Passed	Passed	Passed	Passed	Failed	Failed
17	Passed	Passed	Passed	Passed	Failed	Failed
18	Passed	Passed	Passed	Passed	Failed	Failed
19	Passed	Passed	Passed	Passed	Passed	Failed
20	Passed	Passed	Passed	Passed	Passed	Failed
21	Passed	Passed	Passed	Passed	Passed	Failed
22	Passed	Passed	Passed	Passed	Passed	Failed
23	Passed	Passed	Passed	Passed	Passed	Failed
24	Passed	Passed	Passed	Passed	Passed	Failed
25	Passed	Passed	Passed	Passed	Passed	Passed

Note. All participants passed the ABLA levels 1 to 3 (not shown in table).
ABLA level 4 = visual match-to-sample discrimination; 2-choice matching sound = 2-choice task to produce a matching sound; ABLA level 6 = auditory-visual combined discrimination; 2-choice nonmatching sound = 2-choice task to produce a nonmatching sound ; AAIM = auditory-auditory identity matching. AANM = auditory-auditory nonidentity matching.

Order analysis was used to test the hierarchical relationship between adjacent discriminations (Krus, Bart, & Airasian, 1975), using a binomial distribution for pass and fail occurrences (Conover, 1980). For each pair of adjacent discriminations tested, a participant who passed the presumably less difficult task and failed the more difficult one was considered a Confirmation (C), whereas someone who failed the presumably less difficult task and passed the more difficult one was considered a Disconfirmation (D). Participants who passed or failed both tasks were excluded from the analysis because their performance did not indicate which discrimination was more difficult, and therefore, did not contribute information on the order of the two discriminations. A standard score was derived by the formula: $z = (C - D) / \sqrt{(C + D)}$ (Kerr et al., 1977). The order analysis of the present results is shown in the top portion of Table 4. Comparisons 1, 2 and 5 were statistically significant. Comparison 3 was not significant and Comparison 4 was not evaluated because only one participant was at that level.

Because the 2-choice tasks to produce matching and nonmatching sounds were similar to those used in previous studies (Lin et al., 1995; Walker et al., 1994; Ward, 1995), we combined the present results with data reported in those studies. The combined results showed that Comparison 4 was statistically significant, by increasing the number of confirmations from 1 to 12, and further enhanced the significance of Comparison 5, by increasing the sample from 5 to 25 (see Table 4, bottom section). The study by Ward contributed one participant (a disconfirmation) to Comparison 4. Therefore, the hierarchical position of the 2-choice task to producing a nonmatching sound was inconclusive. We note that all other relationships that were statistically significant, based on data from this study or from combined results, were established without any disconfirmations.

Discussion

The present results, in conjunction with those of Walker et al. (1994), Lin et al. (1995), and Ward (1995), provided strong evidence that the

Table 4

Order Analysis

Comparisons[1]	Confirmation	Disconfirmation	z
Results from this Study			
1. AANM > AAIM	6	0	2.45†
2. AAIM > 2-Choice Nonmatching Sound	9	0	3.00‡
3. 2-Choice Nonmatching Sound > ABLA level 6	3	0	1.73
4. ABLA level 6 > 2-Choice Matching Sound	1	0	--
5. 2-Choice Matching Sound > ABLA level 4	5	0	2.24†
Results Combined with Previous Studies			
3. 2-Choice Nonmatching Sound > ABLA level 6[2]	3	1	1.00
4. ABLA level 6 > 2-Choice Matching Sound[3]	12	0	3.46§
5. 2-Choice Matching Sound > ABLA level 4[4]	25	0	5.00§

$^{\dagger}p < .05$; $^{\ddagger}p < .01$; $^{\S}p < .001$.

1 In each comparison, the "greater than" symbol represent "more difficult than."

2 Ward (1995)

3 Lin et al. (1995), Walker et al. (1994), and Ward (1995)

4 Lin et al. (1995), Walker et al. (1994), and Ward (1995)

2-choice task to produce a matching sound falls between ABLA levels 4 (matching-to-sample) and 6 (auditory-visual combined discrimination), and that the auditory-auditory identity and nonidentity matching tasks are hierarchically ordered beyond ABLA level 6. Of the four auditory discriminations added, it appeared that at least the two-choice task to produce a matching sound could be used as an intermediate training target between levels 4 and 6. Regarding the two auditory discriminations that were ordered beyond ABLA level 6, they could be used to further differentiate the skills of students previously grouped as ABLA level 6.

Future research is needed to evaluate the practical utility of these discriminations. For example, will the training of ABLA level 6 be more effective if the 2-choice task to produce a matching sound is used as an intermediate training step? Do the additional auditory discriminations possess characteristics similar to the original ABLA tasks, such as resistance to change, high test-retest reliability, and predictive validity of similar auditory discriminations?

The current study has several limitations. First, it would have been desirable to have a larger number of participants for the order analysis. Despite the small sample, four of the six comparisons were statistically significant based on our current data, and five of the six comparisons were statistically significant when the results were combined with previous studies. Moreover, all statistically significant comparisons were also supported by individual data without exception (no disconfirmations). Future studies with additional participants, especially between ABLA level 6 and the rice and rattle task (a two-choice task to produce a nonmatching sound), would be desirable.

Another limitation is that our sample did not include individuals who passed ABLA level 5, but failed level 6. During baseline, we did not encounter any one at this level after screening 50 individuals. It appears that previous studies also found few individuals at ABLA level 5. There was no one at this level out of 12 participants in Lin et al. (1995) and only one out of 31 participants in Walker et al. (1994). One possibility is that individuals who pass ABLA level 5 subsequently pass level 6 in a relatively short time. The absence of participants at ABLA level 5 in this study, however, does not weaken the observed results. A third limitation is that we did not determine to what extent a participant's prior knowledge of the word pairs spoken in the two most difficult auditory matching tasks contributed to their performance. It may have been preferable, from a research perspective, to use nonsense syllables in these tasks. However, accepted practice for assessment, research, and training with persons with developmental disabilities indicates that tasks and prompts should have functional value for the participants (Favell & McGimsey, 1993; Van Houten et al., 1988). The generality of the results related to these two tasks could be strengthened if different word pairs are used in future replications.

A fourth limitation is the possibility of experimenter bias since the tester was not blind to the purpose of the study. Partly for this reason, we conducted reliability checks on a large number of sessions. The high percentage agreement obtained for interobserver and procedural reliabilities, coupled with the fact that five different assistants conducted reliability assessments throughout the study, suggest that experimenter bias was an unlikely explanation of the findings.

In summary, this study identified several auditory discriminations that are hierarchically ordered and related to the ABLA tasks. These tasks have the potential to extend the practical utility of the ABLA test.

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Addressing Grief and Loss in Adults with Developmental Disabilities

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This paper addresses the problem of grief and loss in adults with developmental disabilities, and the lack of a systems-based model of assessment and intervention. The discussion reviews the existing literature in the area of loss and developmental disabilities and proposes an expanded conceptualization of loss based on our clinical experiences. Grief responses of people with developmental disabilities are summarized, as well as the responses of the various systems involved with them. The concept of complicated grief is applied to this population, with recommendations for systems-based interventions. A model for a bereavement group and individual treatment is presented. These examples support the need for a systems-based orientation for those working with bereaved adults with developmental disabilities.

The issues of loss and bereavement are familiar ones to those who are involved with adults who have developmental disabilities. Unfortunately, there is little recognition of the impact of loss on this population. Usually with this group, the definition of loss tends to be a traditional one (i.e., death) rather than inclusive of the whole range of losses that an individual with developmental disabilities may experience (i.e., change of care givers, loss of life dreams). Even when there is recognition of the impact of losses on the individual, people who make up the person's support system may be unsure how to address losses; they realize that failure to do so may adversely affect the quality of life of the individual suffering the loss. Fortunately, there are several examples of bereavement interventions in the literature; conceptual models of intervention appear to be lacking completely.

The purpose of this discussion paper is to review the relevant loss literature for people with developmental disabilities, redefine loss, expand the analysis of the loss process so that it includes systems-based assessments and interventions, and to review areas for future consideration. We will present a practice model that includes bereavement groups and individual assessments and interventions, based on the our clinical experience.

Literature Review

Since Kubler-Ross (1969) wrote her pioneering book, *On Death and Dying*, much has been written and taught about the grieving process. Kubler-Ross described five stages of grief responses: (1) denial, (2) bargaining, (3) anger, (4) depression, and (5) acceptance. It is commonly acknowledged that these stages are not mutually exclusive and that a bereaved person may proceed through them with regression to earlier stages. It has also been noted that the emotional tasks necessary for successful transition through a loss are: (1) accepting the reality of the loss, (2) experiencing the pain of grief, (3) adjusting to an environment without the deceased, (4) withdrawing the emotional energy from the relationship with the deceased, and (5) reinvesting it in new relationships (Worden, 1982).

Deutsch (1985) cited six reasons for the lack of emphasis on grief counselling for people with developmental disabilities. One reason is the inadequacy of care givers and family addressing the topic of death with the person with developmental disabilities. Deutsch further argued that others hold the beliefs that these individuals do not understand death; that they are incapable of forming attachments; that they will forget the person due to cognitive delays; that they should be spared any unnecessary stress; and that acceptance of the loss would be easier if information about the loss was shared over an extended period of time. In attempting to dispel these beliefs, Deutsch pointed to the need to address bereavement issues through education, catharsis, relaxation techniques, imagery, role playing, and cognitive therapy.

Hollins (1995) suggested nine strategies for care givers dealing with bereaved individuals with developmental disabilities: "(1) be honest, include and involve; (2) listen and be there; (3) actively seek out non-verbal rituals; (4) respect photos and other mementos; (5) minimize change; (6) avoid assessment of skills; (7) assist searching behaviour; (8) support the observance of anniversaries; and (9) seek specialists for consultation if behavioural changes persist" (p. 51). Similarly, McDaniel (1989) reported that participants of a bereavement group for persons with developmental disabilities expressed two substantive concerns: they felt excluded from the period when their family member was ill, and they worried about who would care for them when their parents died. McDaniel pointed out that the success of the group was due to both the verbal skills of the clients and staff support in the setting of goals for individuals in the group.

Redefining the Nature of Loss

Bereavement counselling is commonly understood as relating to the death of a loved one. Based on our clinical experience, we have concluded that in supporting adults with developmental disabilities, it is important to consider the wide nature and variety of their losses. Unlike others, individuals with developmental disabilities have close dependent relationships with a wide range of people such as therapists, group home staff, community workers, and/or Adult Protective Service Workers. In many cases, the individual may have close relationships with countless paid care givers over the course of their lifetime. Due to job changes, budget cuts, changes in services, or in their treatment plan, the individual may have little or no control over the departure of these people from their lives.

Just as they endure the losses of those who support them, adults with developmental disabilities experience the loss of their peers. For example, one of the authors is involved in counselling a woman who was deinstitutionalized in her late forties. While she lived in the institution, she had a boyfriend who also resided there. After she left, those supporting her tried to help them to maintain contact with each other, but this was difficult because of the physical distance between them. Sadly, after being deinstitutionalized, the woman acknowledged that their relationship could never be the same as it was before.

The third type of loss which often is not considered in adults with developmental disabilities is the loss of their dreams and hopes. Such losses include forfeiting their dreams of the type of work they want, their desired living situation, wishes about their love relationships, and having children. Realization and acknowledgment of such issues may be especially salient for people with mild cognitive delays because they may be aware of their differences when they compare themselves to unaffected peers.

The fourth type of loss which affects people with developmental disabilities is "exaggerated" anticipatory grief or loss. In other words, they may be overly anxious about future deaths or losses. These concerns may appear even when those who support them are not ill, or there is no indication of a departure of these people in the near future. This anxiety may be interpreted as a symptom of their recognized dependence on others, of previous unresolved losses, or both.

Grief Responses of Individuals with Developmental Disabilities

For the purposes of this paper, grief responses involve accepting the loss, experiencing grief, adjusting to an environment without the deceased, withdrawing the emotional energy from their relationship, and reinvesting it in new relationships (Worden, 1982). Some indicators of an individual going through this process may include: behavioural changes, mood changes, isolation, difficulties in relationships, decreased activity and motivation levels, fluctuations in eating and sleeping patterns, and difficulties concentrating. These indices are experienced in people with and without developmental disabilities.

There are, however, some unique factors to note when considering the grieving process in people with cognitive delays. For example, the problems that people with developmental disabilities have in expressing their feelings is important to recognize when discussing their grief reactions. This issue is especially salient for those who cannot communicate verbally. Ludwig (undated) discussed the difficulty that many people with developmental disabilities have in interpreting the meaning and the feeling content in the facial expressions of others. This influences their ability to identify their own feelings which may, in turn, impair the expression of their feelings related to their grief.

It has been our experience that the individuals we support have many misunderstandings about the expressions of emotions, or are suggestible when it comes to expressing them. For example, our clients may associate "bad feelings" with "bad behaviour" and therefore have difficulty expressing emotions such as anger or sadness. This may be a result of the inability of service providers to help them successfully differentiate between acceptable emotions (e.g., anger) and inappropriate behaviours (e.g., aggression). As well, in bereavement groups we have seen adults display emotions that we have told them are appropriate given the discussion, rather than display them because they are truly experiencing them. This reflects the tendency for our clients to want to please, which is a issue of concern in a multitude of clinical situations for this population.

Systemic Responses to Loss Involving Individuals with Developmental Disabilities

Systems theory emphasizes the interdependency of parts of a system, such as a family (Leighninger, 1977; von Bertalanffy, 1962; Walsh, 1982). According to this approach, it is reasonable to predict that the loss of one member of a family will dramatically affect all members of the system, and the impact will resound throughout the system (Gelcher, 1983). A common scenario seen in family and individual therapy involves an adult and their surviving parent coming to address behaviour problems. Often, the bereaved parent finds it difficult to both deal with the loss of their spouse and meet the needs of their dependent son or daughter. The problems are exacerbated if the parent who died was the parent primarily responsible for the care of their child, or was perceived as the disciplinarian in the family. The implication for treatment therefore involves working with the whole system (i.e., the family), not just a part of it.

Another problematic systemic response is apparent in the belief that people with cognitive delays cannot deal with distressing events or process loss. This may be demonstrated by the exclusion of individuals from bereavement rituals, withholding information about the impending death of the loved one, or by removing them from (or failing to include them in) situations which are unpleasant near the time of the loss. As a result of this protective stance, the individual does not have the chance for anticipatory grief. Most evidently, education about death, dying, and loss are not commonly a part of the culture of people with developmental disabilities.

Three remaining issues are of note when one considers systemic responses to loss in this population. First, of all the needs that our clients face, fulfilling emotional needs may be a lower priority for careproviders given the pressing demands to provide instrumental support to people who require assistance in daily living. Second, given the considerable turnover in staffing, careproviders who are there to support the person in time of grief may not know the nature of the relationship with the loved one. Third, if the bereaved person is involved with a variety of systems, the demonstrations of the grief may be apparent in some settings and not in others.

Complicated Grief Applied to Adults with Developmental Disabilities

For the purposes of this discussion, complicated grieving is defined as the avoidance of grief or a chronic, delayed or inhibited grief response. Complicated grieving from unresolved multiple losses and the possibility that earlier losses have not been fully resolved has been well described with respect to the nondisabled population (e.g., Skinner-Cook & Dworkin, 1992). This concept also is relevant when discussing grief and loss issues with respect to people with developmental disabilities. We believe that the majority of bereaved clients seen in our clinical practice experience complicated grief. There are several issues to recognize when considering the possibility of complicated grief in people with developmental disabilities. First, a loss may occur while substantial developmental, personality, or emotional issues remain unresolved. It is necessary for the therapist to assist in resolving the underlying issue(s) before the grieving process can be completed. For example, the developmental needs of our clients may not be adequately addressed prior to a loss. Because our clients have exceptional needs, a mutual dependency may develop between the primary care giver (usually an aging parent) and the adult child which can consequently leave the adult survivor unskilled and unprepared for losses and the future. Often there have been no plans made for the adult child on the passing of the parents. Similarly, when personality disorders exist (such as Borderline Personality Disorder) prior to a loss, the bereavement process may be difficult to resolve because of the individual's characteristics. In fact, personality disorders may be heightened with such a loss, and future treatment approaches and goals may have to be modified accordingly.

Second, a delayed grief response may be evident for those individuals who have not adequately addressed previous losses. Delayed grief is indicated when a current loss or other traumatic event triggers an unreasonably exaggerated grief response in the person who has not yet successfully completed an earlier grieving process. Previous losses may be unresolved because they were unrecognized as such, the individual was overprotected, their previous history of losses is unknown, or the loss could not be dealt with due to circumstances. There also may be grief responses arising from totally unrelated events. It is common that the bereaved with developmental disabilities may not have resumed regular daily functioning years following the loss.

Three, in people with developmental disabilities, the stage of anticipatory grief is as important in ameliorating a loss as it is in the typically developing population. In any circumstance where the loss is unusual or there is no warning, as in a suicide or a motor vehicle accident, the loss would feel magnified because there was no opportunity for anticipatory grieving. Based on our clinical experience, individuals with developmental disabilities have even more difficulty than others when trying to make sense out of this type of loss. Many of our clients are not informed of an impending loss by care givers as they feel the need to protect them. This in turn, keeps them from anticipating and preparing for the loss.

Four, individuals with developmental disabilities may be more influenced by the avoidance of grief issues by others. If for example, the deceased person's room is unchanged for a long period after their death (known as mummification), one may suspect the avoidance of grief. People with developmental disabilities tend to be concrete thinkers and may interpret this preservation as an indication that death is not final and may be reversible. Likewise, if people around the individual continue to focus on feelings of anger and guilt and are not able to say goodbye, one might expect avoidance on the part of the individual with developmental disabilities.

Five, inhibited or masked grief reactions are common in people with developmental disabilities because they cannot always express verbally the many feelings involved in grief. This difficulty may result in behaviour problems. Behavioural indications of inhibited grief may include suicidal thoughts and plans, criminal actions, promiscuity, chronic pain, or other psychosomatic complaints.

Six, many diagnosed psychiatric disorders such as depression, anxiety, eating disorders and post-traumatic stress could be signs of complicated grieving. Approximately half of the population of people with developmental disabilities are dually diagnosed (i.e., a cognitive deficit and a psychiatric or behavioural disorder). Day (1985) found that as many as one half of people with developmental disabilities admitted to a psychiatric setting had recently experienced illness or loss of a loved one or care giver. Therefore, it is vital that a therapist clarify the possibility that loss may be related to mental health problems.

Seven, historical factors may predispose someone to have a more complicated grieving process. These factors may include a dysfunctional family, inadequate support systems, multiple losses, ambiguous loss, or when the relationship with the deceased was problematic (Skinner-Cook & Dworkin, 1992). Unfortunately, these historical factors may not be known by the care givers involved with the individual due to the inability of the individual to report them, changes in support systems, or scant information on file.

Eight, because individuals with developmental disabilities often are dependent on care givers, the loss of a care giver may be perceived as more traumatic than it would be for more independent people. This is especially true in cases where individuals with developmental disabilities are unskilled or not encouraged to attain the highest level of independence by family or supports in preparation for the time when a care giver dies or can no longer provide care. Also, because people with developmental disabilities often have difficulty making friendships and experiencing a wide range of significant social contacts and emotional attachments, the loss of a care giver may be quite traumatic (McLoughlin, 1986).

A Systems-Based Model of Assessment and Intervention

Figure 1 depicts the usual progression of the grief process in people without developmental disabilities through the period of the illness, the death, the funeral, the marking of rituals, and an eventual return to healthy family coping. When people successfully resolve their grief, they are better prepared to cope with subsequent losses. Figure 2 demonstrates when and where persons with developmental disabilities get left out of the grieving process and therefore develop interrupted or complicated grief cycles. They first lack information about death in general or an impending death in the family. After the death, they may be told nothing or little about the death. This in turn may exclude them from family and others' support and in fully participating in rituals such as the funeral and other meaningful events which mark the death. Isolation from family or drastic changes in the person's life (such as a move to a group home) may further exacerbate the individual's ability to deal with the loss. When these events occur, the person with developmental disabilities may continue to suffer the effects of the loss and may have fewer resources with which to deal with any future losses.

Grief and loss issues in people with developmental disabilities challenges the system. Table 1 summarizes the systems problems previously identified which include: (1) lack of information, (2) dependence,

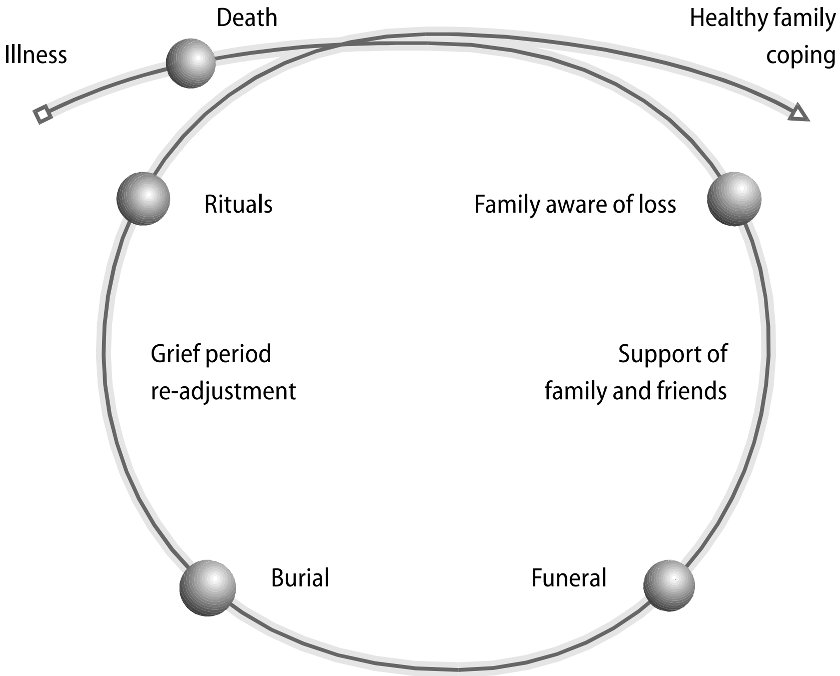
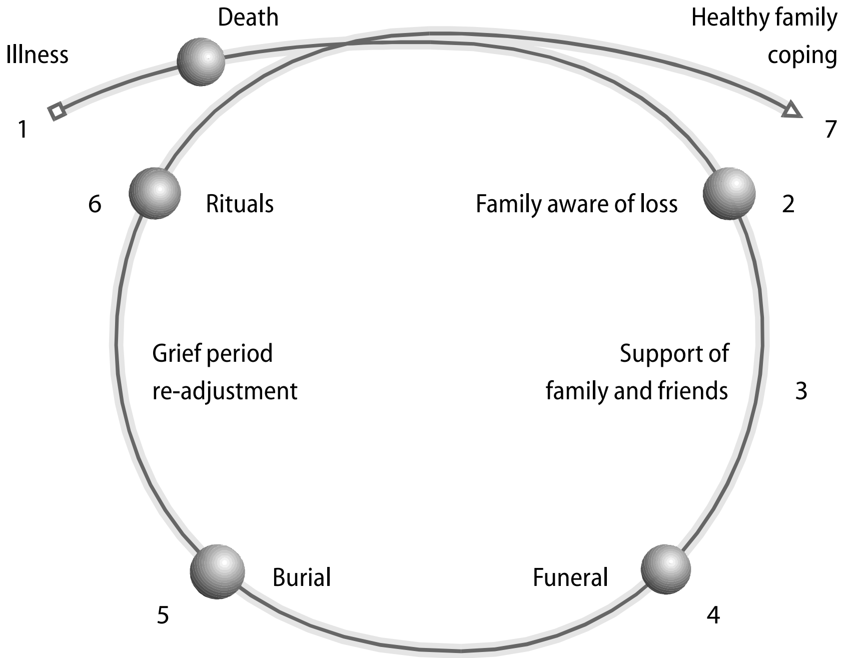


Figure 1
A healthy, systemic family response to loss

(3) non-inclusion in rituals, (4) overprotectiveness, (5) family conflict, (6) lack of supports, and (7) isolation from family. The accompanying interventions may occur in group, individual, and family counselling. This model is based on the need for a revised conceptualization of the problems and treatment appropriate for people with developmental disabilities based on a systemic understanding of their difficulty in processing a loss.



1. Lack of general information about death and knowledge of loved one's illness
2. Lack of information and involvement
3. No opportunity for support
4. May not be included
5. May not be included
6. Difficulty marking rituals
7. Isolation from family

Figure 2

Potential points of interruption in the grief process of persons with developmental disabilities.

Bereavement Groups

Bereavement groups are commonly used in supporting people through a variety of losses (e.g., Yalom & Vinogradov, 1988). We offer a structured, time-limited bereavement group for adults with developmental disabilities. The bereavement group has five goals: (1) to allow individuals to share their experiences and emotions surrounding their loss, (2) to provide members with information regarding grief and mourning process, (3) to make them aware that their reactions to such a loss (including anger) are not unique to them, (4) to help them move toward creating a new life for themselves without the deceased, and (5) to assist with the mourning process in an attempt to reduce the potential for unresolved or distorted grief. Topics covered in the group include memories of the loved one; manifestations of grief; and education about illness, death, and the funeral. Feelings and healthy coping techniques are also discussed including saying goodbye to the loved one, the length of the grief period, and how to deal with difficult times (e.g., Christmas, anniversaries). Leaders prepare materials for each session and also allow for impromptu discussions. Various methods are used to encourage group participation including whole group discussion; sharing in dyads; showing significant objects or pictures, audiovisual activities which help the clients cope; journal writing; homework assignments; and certificates of participation. Clients are screened prior to the group with their support person(s) and a follow-up interview occurs after the group ends. Further recommendations for therapy (individual, family, or group) may be made.

Clients are excluded from participation in the bereavement group if they are: (1) in crisis; (2) unable to complete group tasks due to their communication ability, functioning level, ability to attend, or psychosis; (3) exhibit serious and uncontrolled aggression; (4) do not have the support of their family, care givers, or group home staff ; (5) have shown themselves unsuitable for groups in the past; or (6) are not yet ready to grieve due to denial or an insufficient period of time since the death.

Table 1

Summary of Systems Problems, Interventions, and Desired Outcomes

Systems Problem	Systems Intervention	Desired Outcomes
1. lack of information	education	Resolution of grief and preparation for the future
2. dependence	work toward independence	
3. non-inclusion in rituals	inclusion in rituals	
4. overprotectiveness	appropriate control	
5. family conflict	mediate conflict	
6. lack of supports	increase support system	
7. isolation from family	support family interactions	

Case Example

The following case example demonstrates how the systems-based formulation of an individual's grief process led to a variety of interventions using individual, group, and family therapy modalities. "Bob," was 28 years old with mild delay who was referred by his mother. She expressed concerns about Bob managing his money, carrying a knife in order to "feel safe," destroying his belongings, being unemployed, and feeling depressed. His father, to whom he was very close, had died a year previously. Bob had been prescribed a brief trial of antidepressant medication by a community psychiatrist, but this did not ameliorate his depression. Bob had worked directly with his father, but was unable to successfully carry out his job after his father's death. He became extremely isolated at home without his father to take him to recreational outings, and he had few ongoing social contacts. This was the first time for many years the family had contacted a service provider.

Several interventions were offered to Bob. Individual therapy focussed on how his life had changed since his father died and how he could have a happy life even with his father gone. He also attended the bereavement group. Bob discussed his perception that his mother did not fully disclose the details of his father's illness just prior to his death and he was angry that he was not able to say goodbye. Family work focussed on conflict resolution and provided a forum for Bob and his mother to discuss their common loss. He also expressed concern about the future when his mother would no longer be there to help him. A speech assessment was completed in order to determine his language skills and recommendations were made to help him be more expressive with others. Behaviour therapy focussed on developing money management and other life skills (e.g., laundry and cooking). He enrolled in a social skills group. A psychological assessment determined Bob's intellectual functioning and proposed possible work options. These options were then pursued by the case manager, who also referred him to recreational activities. Within a few months, Bob reported marked improvement in his functioning and mood without the use of medication.

Future Directions

This paper has summarised types of grief that people with developmental disabilities may experience. We discussed conditions under which complicated grief may occur and outlined systemic responses to it. A model for a systems-based intervention was offered that encompasses both group and individual modalities. Future work should focus on: (1) increasing understanding of how people with developmental disabilities experience and express emotions and respond to losses, (2) establishing more sophisticated ways to measure treatment outcomes with respect to this issue in this population, and (3) further educating service providers about the importance of addressing grief and loss in this population in order to improve their quality of life.

Acknowledgments

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Stepping Back to Look Ahead: Evaluation of a Mary Centre Residential Program

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We describe a program evaluation of a group home for seniors with developmental disabilities operated by a non-profit community agency. The evaluation was conducted internally with front-line staff, family members, and residents involved. Challenges and benefits of conducting an internal evaluation are discussed. The results indicated that staff enjoyed working with the residents and felt that their work was meaningful. Families were pleased with the quality of care and indicated that they wanted to have more input into their relatives' lives. Several resident issues emerged from the evaluation. These included modification of the environment to allow residents to function more independently despite physical limitations; the need to promote more positive resident to resident interactions; increased staff understanding on how the aging process may impact on the residents' behaviours and skills; and recognition that staff may have expectations that exceed the residents' abilities.

There is a phrase attributed to Confucius – "May we live in interesting times." This quote seems to be an understatement during the '90s, as we constantly change to meet demands, both new and old. For agencies supporting people with developmental disabilities, we have become accustomed to terms such as accountability, effectiveness, efficiency, and quality of life. Being financially responsible while meeting the needs of the agency's clientele has been a prominent theme of the times.

Mary Centre is one such agency that recognizes the importance of its residents and their quality of life. As a result, an evaluation was created to look at its residential program. A relatively simple process began by involving front line staff. Staff agreed that it was time to take a look at how services were offered at the original residence because, at the time, it had been operating for five years. A small group of staff committed themselves to developing this process, be responsible for collecting and analyzing information, and providing recommendations. The evaluation was large in scope and it incorporated residents, staff, and family members. The purpose of the evaluation was to look at the service provided from three perspectives in order to help provide a good quality of life for the residents. First, staff satisfaction was explored because their satisfaction can influence how service is provided and, ultimately, impact on the residents' lives. Second, families were asked to identify areas believed to be important for the care of their relatives and how Mary Centre measured up in providing that care. Third, several resident-focused issues were identified by the staff.

Description of Mary Centre

Mary Centre is a non-profit organization that supports people with developmental disabilities in the Greater Toronto area. Services include residential and community support programs. Residential programs consist of two homes in Brampton for adults, three homes in Toronto for seniors, and Supported Independent Living apartments in Toronto, Woodbridge, and Brampton. The community support programs include an Integrated Seniors' Program in Toronto, a Volunteer Program, and a Parish Outreach Program (that encourages parishioners to respond to the needs of people with developmental disabilities within parish life).

The evaluation took place in a Toronto home that accommodates four seniors. At the time, three women and one man over the age of 50 lived in a five bedroom wheelchair accessible bungalow. Each resident had varying degrees of disability. Two people had Down syndrome, one had cerebral palsy and used a wheelchair, and the fourth person had Tourette's syndrome. At least one staff person was on duty at all times. The staffing consisted of five full time staff, four of whom were primary counsellors and one who covered the overnight awake shift. In addition, several part time staff worked on a regular or relief basis.

Challenges and Benefits of the Evaluation

The evaluation was conducted by a small committee of four people consisting of front line staff from the residence and senior management. All staff recognized the importance of doing an evaluation.

Challenges

Several challenges were faced. First, inexperience in program evaluation and conducting a research-oriented project led to uncertainty as to how to proceed. Considerable time was spent determining the intent of the evaluation and how to fulfill those expectations. Second, we countered difficulty finding suitable materials that provided clear guidelines on how to conduct a program evaluation involving people with developmental disabilities. Third, finding the time for the evaluation was an obstacle. The evaluation activities were juggled around the needs and schedules of the residents and staff. Furthermore, the time spent gathering information, preparing for meetings, and attending meetings took time away from the residents. Fourth, although the methods devised to gather information were meant to be objective, there still was a risk of bias because front line staff collected the data.

Benefits

Despite the challenges experienced with the project, they did not outweigh the benefits. Staff involvement allowed them to discover the importance of doing an evaluation, identify issues that are of key importance to the residents, and achieve “buy-in” to recommendations made by team members. Staff were more willing to accept new ideas and make changes when the recommendations were seen as derived from within, as opposed to criticisms from an outside source. The acceptance of the recommendations was, and continues to be, critical to the success of the evaluation process.

The evaluation resulted in the staff focusing more intently on the care that they provide to the residents. The evaluation experience enabled staff to be more reflective and self-critical. They were able to think critically of the service and where changes should and could be made. The evaluation process allowed staff to step out of their usual role, be visionary with respect to Mary Centre's services, and gave them a sense of control and responsibility in having a larger role to play in the agency. The internal evaluation was a relatively low cost venture, presumably significantly lower than the expense of hiring a consultant. The evaluation process became an incredible learning tool for the staff. The commitment to providing quality care and monitoring that provision of care has been ongoing since completing the project.

Staff Satisfaction and Family Perspectives

The project was quite extensive and it was beneficial to explore staff satisfaction and family perspectives. In terms of staff satisfaction, people enjoyed working with the residents and felt that they had a job which was important and meaningful. Furthermore, areas of change focussed on team work issues as opposed to concerns with the residents or agency. Families felt that quality care was provided to the residents and the staff were seen as instrumental in providing this care. By including the families, staff realized that families were unaware of their relatives' achievements, and to a certain degree, wanted to have more input into their relatives' lives.

Resident Issues

The comprehensive nature of the project allowed us to explore resident issues in detail. Staff identified three areas of concern with respect to the residents. First, the tasks and daily routines of residents were studied to determine if changes in these routines were required to make life easier. Second, the relationships among residents and between residents and staff were explored. Third, the expectations that are placed on residents and the relevance of these expectations were identifed.

Accommodations for Daily Tasks

Information regarding the residents' daily routines and tasks was easily accessible through agency records and observations. Staff and resident meeting minutes and resident monthly reports over a one year period were examined to determine if areas of difficulty for the residents had been noted. In addition, staff observed residents during high task demand periods. Committee members completed a data sheet that identified the difficult tasks for each resident and behaviours indicating this difficulty. For example, an observation may be that a resident had difficulty putting dishes into the dishwasher from her wheelchair, and she complained of no longer being able to do anything.

From the various sources, numerous challenging tasks were identified. Changes were needed to make tasks easier for the residents while maintaining their independence. Staff identified areas of priority for change as they did not want to overwhelm the residents with a large number of changes. As well, limiting the number of changes was important from a staff perspective as they needed to remember all the changes that were made in order to be most supportive to the residents.

To provide a better understanding of the changes that were made, an example is provided. One woman used a wheelchair and had limited movements in her arms and hands due to cerebral palsy. Three daily living tasks for which she was responsible included putting her dishes in the dishwasher, clearing the dining table of condiments, and brushing her teeth. It was noted that she became frustrated putting dishes in the dishwasher because she could not find a space within her reach to rest the dishes. Therefore, she had to make many trips back and forth from the kitchen to the table because she could only carry one item at a time. Similarly, being left handed, she struggled to reach her teeth brushing supplies because they were on the right hand side of the bathroom vanity. Suggestions to make these chores easier for her and maintain her independence included staff re-arranging dishes in the dishwasher to create an open space in which she could reach and place her dishes;

attaching a tray onto her wheelchair to help her clear the table and decrease the number of trips to the kitchen; and purchasing a separate holder for her teeth brushing supplies which was placed on the left hand side of the counter.

These changes were simple and effective; one of the benefits of this type of evaluation was that recommendations were practical in nature. These practical changes can definitely impact on quality of life if a resident then is able to function more independently with less frustration. By deliberately looking at the routines of the residents, staff became conscious of the difficulties experienced by the residents on a day to day basis. Many changes were noted by staff to be very positive for the residents. The residents may not have specifically commented on the changes; however, the staff noticed the residents completed their respective chores with greater ease. The process of evaluation has become integral to the residence and continues to be monitored and adapted as necessary. Sometimes the residents were not completely comfortable with some of the changes and would usually express their displeasure. However, staff continued to work with them to find the best solution.

Relationships

To assess the quality of relationships among residents and between staff and residents, observations of interactions were made over a four week period. Committee members were responsible for recording the data and may have been directly observing an interaction or participating in an interaction. Staff collecting the information recorded the time of the interaction, who was participating, the physical location of the people, the tone of the interaction, body language of the individuals, and any additional comments needed to accurately describe the situation. Interactions could include verbal and non-verbal forms of communication. Data were collected throughout a shift as interactions occurred. Ongoing responsibilities of staff led to some difficulties in recording information. Many times staff forgot to record information or data were recorded retrospectively. This may have biased the results because many interactions may have been missed or negative incidents had a greater likelihood of being remembered and, thus, recorded. Thus, the findings reported below should be interpreted cautiously.

The majority of recorded personal contacts of the residents were with the staff. Although the residents participated in regular activities outside of the house and were encouraged to be involved with their families, the residents tended to interact mostly with staff rather than their housemates, friends, or families. Furthermore, the length of time staff interacted with a resident was usually very brief, less than 30 seconds. The most significant information from the data was the relatively poor relationships residents had with each other. The majority of interactions between residents were negative: yelling at each other, being afraid of, or avoiding, someone.

Staff reactions had a great impact on the reactions of the residents. The evaluation information conveyed the importance of staff: (1) taking the time to really listen to what residents would like or not like to do, (2) taking steps to avoid confrontations and power struggles, and (3) recognizing the benefits of being positive in their approach no matter how difficult a situation may be. The staff expressed a desire to spend more quality time with the residents. The staff felt that spending one-on-one time with residents while they did some of their daily tasks could lead to more interactions and improved relationships and, ultimately, increased quality of life. Staff realized the importance of the residents becoming more involved in house responsibilities such as meal preparation, laundry, and vacuuming while considering each resident's capabilities and the supports needed to encourage his/her involvement.

The interactions between residents was a critical aspect to consider in a group home setting because residents spent so much time together in relatively confined quarters. This became apparent when working with the seniors population because typically more leisure time is spent within the home than with younger residents. Because the quality of one's relationships can influence one's level of happiness, it is crucial to assess housemates' compatibility in the admission process. At the time, the residents living in the home did not have much choice in deciding where or with whom to live. However, the evaluation made clear that their involvement in deciding on future housemates would be imperative. The personalities of the present and future residents must be carefully considered. Changes have been made to provide those residing in the house with more opportunities to describe the kind of person with whom they would prefer to live. As well, more time is given for a prospective resident to get to know the other residents, the staff, the house, and expectations before a decision is made for permanent placement.

Expectations Placed on Residents

With respect to the expectations placed on the residents, both part time and full time staff provided input. They used agency daily and monthly reports of the residents as well as direct observations to gather information. Staff identified expectations that were placed on residents and described resident behaviours indicating where the expectations may be too high or too low. From the information collected, the expectations were categorized into five groups: (1) to like/respect one another, (2) to use appropriate dinner manners at all times, (3) to be able to make choices independently, (4) to be able to reason or rationalize in a variety of situations, and (5) to express themselves appropriately.

Residents varied in their ability to meet these expectations and differed in the degree of support required to meet them. However, staff came to realize that, depending on the resident, they may have to change their level of expectation in order to match the residents' abilities. Some staff indicated that they see the residents just like anyone else and, as a result, may have overly high expectations of them. Sometimes staff did not take into account the residents' limitations, particularly with respect to their ability to rationalize and demonstrate appropriate behaviour. As well, the staff may not always have considered the effects of the aging process on the residents' capabilities. The evaluation highlighed the importance of addressing the staff's expectations of the residents on an individual basis.

Two examples illustrate how staff readjusted their expectations after the evaluation. In the first example, staff often expected residents to handle conflicts calmly and appropriately, rather than get angry with each other and yell or swear. The staff assumed that the residents would sit down and discuss the situation to try and understand each other's perspective. Staff came to realize that they needed to determine whether, in fact, a resident had the ability to empathise with others before anticipating that resident would express his/her feelings calmly and constructively. The second example was staff's requirement of appropriate dinner manners at all times. This created stressful meals as people were being constantly reminded what *not* to do. Staff recognized the importance of placing priorities on certain manners that related to safety issues and being polite. Staff continued to stress the importance of not talking with one's mouth full, to say please and thank you, and to ask others to pass things rather than reaching across the table. Staff backed off on other more minor transgressions and withheld their comments and prompts. Staff no longer responded to pushing food onto a fork with fingers, or having one's elbows or arms on the table while eating.

As a direct result of the evaluation, staff were able to self-examine values and assumptions in a constructive way to enable appropriate changes in their expectations. Staff learned to identify expectations that promoted independence and challenge the residents to learn more, but that did not overwhelm the residents' current abilities and create feelings of failure for both the residents and staff. Either too high or too low expectations can compromise one's quality of life. In addition, each individual has a differing perspective on what is appropriate and inappropriate behaviour and this will influence expectations on oneself and others. The evaluation taught staff to become more aware of differing perceptions when placing behavioural expectations on the residents.

Summary

The entire evaluation process was extremely valuable to the staff and, consequently, the residents. They were able to identify issues that had an impact on the quality of life of the residents such as changes to the physical environment to make life easier and compensate for limitations, inaccurate expectations on aging individuals, and the importance of communication and social skills. As well, the process allowed staff to look critically and more objectively at how they provided service to the residents. Staff became consciously aware of how their actions and expectations affected the residents. Staff took notice of things that they may have previously overlooked. The strength of the project has been the staff's focus on the core of Mary Centre, which is the residents. The "real" work has just begun as an ongoing committee at the residence has been established to continually monitor the changes and make adjustments as needed. Staff continually strive to provide an environment that the residents will enjoy. They continue to critique themselves and make necessary changes. The only constant is change as we look ahead to the future.

Acknowledgments

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Responsible But Not Guilty? The Accountability of Persons with Developmental Disabilities or Psychiatric Impairments

The Accountability Working Group
London, Ontario

Executive Summary

Background

About three years ago, concern about how people with mental disabilities (both developmental and psychiatric) were treated in the justice system led to the formation of a group committed to investigating this issue from a broad array of perspectives and making practical recommendations for improvement. At that time (and increasingly so today) the climate was one of "zero tolerance" for violence and aggression. Society was demanding more certain and harsher treatment of offenders. Members of the group shared a sense that this reaction was unjust and counter-productive for persons with developmental disabilities and psychiatric impairments. It is unfair to punish or "consequence" them for behaviour they do not understand or cannot control, and doing so carries the risk of simply increasing the frequency and the severity of their aggressive or violent behaviour.

Members

The Accountability Working Group consisted of a lawyer, a police officer, a psychiatrist, a psychologist, a behaviourist, an educator, a parent, and a philosopher. The group met initially at the Westminster Institute for Ethics and Human Values and then at the Child and Parent Resource Institute (CPRI) in London, Ontario.

Goal

Members of the group do not believe that persons with developmental disabilities or psychiatric impairments should never be subject to the criminal justice system. The principal goal is simply to extend the fundamental tenet of our criminal justice system that persons must possess certain mental capacities in order for the imposition of criminal penalties to be justifiable to these persons. That tenet is exemplified in a section of the *Criminal Code* that exempts children below the age of 12 from criminal responsibility; in recent amendments to the *Criminal Code* that stipulate that a sentence should be proportionate to the gravity of the offence and the degree of responsibility of the offender; and in the provision for diminished forms of criminal responsibility for young people from ages 12 to 17 in the *Young Offenders Act.* Members of the group sought to devise a workable procedure, outside of the criminal justice system for: (1) assessing the accountability of persons with developmental disabilities or psychiatric impairments who commit violent or aggressive acts; and (2) for making recommendations about responses to such behaviour that are fair in light of all the circumstances and that take into account the individual's intellectual and psychological capacities as well as public safety.

Method

The work of the group was always guided by actual events and responses to them. For reasons of confidentiality, the vignettes in the report are disguised. Initially, each member of the group described his or her personal and professional experiences with people who have mental impairments in trouble with the law. Next, scenarios and reactions to them were written and discussed extensively. Then proposals about how current approaches could be improved were devised, criticized, and amended. It took a long time for the group to arrive at a common understanding of the many dimensions of this complicated issue and to agree upon a set of recommendations. The report presents, in a much more compact form, the course the members of the group followed and the destination at which we arrived.

Recommendations

The report contains four recommendations.

Recommendation 1: The recognition of absent or mitigated responsibility for criminally proscribed behaviour embodied in the *Criminal Code* and the *Young Offenders Act* should be explicitly extended to persons whose mental capacities are compromised due, not to age, but to developmental disability or psychiatric impairment.

Recommendation 2: If a person with a suspected developmental disability or psychiatric impairment is taken into custody, he or she should be kept in a protected environment and subject to crisis intervention techniques only if necessary.

Recommendation 3: Because there must be a practical procedure for implementing an approach to determining accountability outside the criminal justice system, each community should form, or have access to, a Consultation Team. The core members of a Consultation Team will be a psychologist, a lawyer, and an informed citizen; people representing other perspectives or disciplines can be added as needed. The Consultation Team will do at least the following:

1. Confirm that an individual has a developmental disability or psychiatric impairment and determine the degree of impairment.
2. Identify other factors, such as the presence of a physical or emotional/thought disorder, that might be relevant to explaining the individual's behaviour.
3. Determine the individual's ability to explain the nature and predict the consequences of the behaviour in question.
4. Determine the individual's ability to control this kind of behaviour in the sorts of circumstances in which it occurred.
5. Determine the best way of responding to this incident and preventing recurrences of this type of incident by this individual.
6. Submit a report and recommendations to the court.

The legal authorization for the work of a Consultation Team and the submission of a report to a court could be derived from the *Criminal Code* amendments that deal with Alternative Measures.

Recommendation 4: The federal and provincial governments should fund the establishment and operation of Consultation Teams (perhaps initially as a pilot project) from the money currently being recovered from the elimination and reduction of social services programs.

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The members of the Accountability Working Group were: H. Dieter Blindert, CPRI; Anna Hampson, Squire, Hampson Law Firm; Cheryl Hartridge, CPRI; Barry Hoffmaster, University of Western Ontario; Steven Prendergast, St. Thomas Aquinas School; Jamie Sheppard, London Police Dept.; Toni Swart, CPRI; and Jean Wright, London. To obtain a copy of the report or for more information contact: H. Dieter Blindert, CPRI, 600 Sanatorium Road, London, ON N6H 3W7.

Book Review

A. Gedye. *Behavioural Diagnostic Guide for Developmental Disabilities*

Vancouver, BC: Diagnostic Books, 1998. 237 pp.

Reviewed by
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Clinicians in the field of developmental disabilities are frequently faced with complex clinical situations where it is unclear what the etiology and subsequent intervention should be for a behavioural challenge. Without a clear diagnostic picture, persons with challenging behaviours are often subjected to intervention that may only partially address aspects of the complex factors that influence the development and maintenance of the challenging behaviour. In many cases, some of the underlying factors that contribute to the behaviour remain undetected.

Numerous articles have been written in recent years about possible contributing psychiatric, biomedical, psychological, social, and environmental influences on challenging behaviour; professional resources on this topic have remained relatively scattered and difficult to access. The *Behavioural Diagnostic Guide for Developmental Disabilities*, by A. Gedye, represents a unique contribution to the field. The stated purpose is to assist the clinician in differentially diagnosing behavioural conditions which may reflect the influence of physical pain, seizures, medication, illness, nutritional deficiencies, psychiatric conditions or environmental influences. It focuses on the complex and often undiagnosed factors that might contribute to or cause the challenging behaviour. Gedye has pulled an extensive list of reference material into what she calls a “catalogue of clues” to determine what conditions underlie certain problem behaviours. The author walks you through the organization of the guide and ways to use the catalogue of clues to best clinical advantage.

The book provides detailed areas of investigation for several of the most common challenging behaviours.

- In Chapter I, the author provides a diagnostic guide to understanding the potential contributions of pain, compulsions, seizures, drug-side effects, delirium, trauma, environmental stimuli or learning on physical aggression.
- Chapter II explores self-injurious behaviour as it relates to pain, seizures, psychiatric states (depression, obsession-compulsion or delusion) and anger, with special sections on eye-poking and self-rubbing.
- Chapter III looks at the various reasons screaming may occur: involuntary or related to pain, distress, trauma, communication, escape, or attention.
- Chapter IV provides information on possible contributing factors for sleep disturbance, including pain, environmental factors, hyperthyroidism, medication, trauma, and psychiatric conditions (such as mania or depression).
- Eating disturbance is described in Chapter V. Pica, excessive eating or drinking, refusal to eat, and swallowing difficulties are explored.
- Dementia as it relates to hypothroidism, depression, folate or vitamin deficiency, medications, and declined functioning due to other physical causes are examined in Chapter IV.
- The final chapter (VII) delineates the possible causes of unwitnessed or unusual falls, including low blood pressure, loss of consciousness, dehydration, over-sedation, heart problems and undetected fractures.
- The book ends with a wealth of references and eighteen added value appendices including a number of checklists and recording charts for various conditions previously listed.

For the discerning clinician in the field of developmental disabilities, this innovative manual should be a welcome addition to a library of diagnostic resources. However, the author appears to suggest the use of the catalogue as a “step by step” diagnostic cookbook. The reader, however, should be cautioned by the author’s introduction that warns that the book is neither a book of strict diagnostic criteria nor does it cover every explanation for challenging behaviour.

The unrecognized and undiagnosed illness and biomedical complications in persons with developmental disabilities and the relationship of these influences on challenging behaviour has been recently documented by several authors (Bosch, Van Dyke, Smith, & Poulton, 1997; Kapell et al.,1998). As such, this new book is very timely in the field. However, I found the author's explanation of the causes of challenging behaviours overly simplistic. Rarely do biomedical and psychiatric conditions directly cause challenging behaviour. In most cases, the physical state represents a contributing condition to a challenging behaviour, but not the sole cause. For example, in the section on *Aggressive Response to a Painful Transient Condition*, the reader is left with the impression that painful constipation or menstrual discomfort is the cause of the aggression. However, aggression does not occur at all times of discomfort, but as a response to some other instigating factor, such as a request or demand or the presence of a particular event. Thus, most behavioural challenges, of a more severe nature, are stimulus complex responses (Gardner, 1998). As such, in addition to the examination of any potential biomedical or psychiatric influences, there also is a need for a systematic analysis of the entire context in which the challenging behaviour occurs (Feldman & Griffiths, 1997; Gardner & Whalen, 1996).

The author has suggested that this book draws attention to a wider range of differential diagnosis for challenging behaviours in persons with developmental disabilities. There is no doubt that this book has indeed explored in depth a different and often overlooked area of diagnostic investigation. The author admits that the book does not address the functionality of the behaviour as a variable. This omission, I think limits the manual in the purpose it was intended. Nonetheless, it is a useful and practical resource, which, if properly used, could greatly benefit clinicians in unraveling the multiple factors that influence challenging behaviour in persons with developmental disabilities.

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Untangling the Web: Finding Information About the Treatment of Autism on the World Wide Web

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There is plentiful information related to treatments for autism and pervasive developmental disorders accessible on the world wide web. However, all treatments are not equal, and with the privilege of abundant information comes the responsibility of evaluating evidence, and making educated treatment decisions. Keep in mind that the diagnostic criteria for autism allow for several permutations and combinations of symptoms. People with autism are a heterogeneous group and it is unlikely that one treatment will prove to be effective for all individuals (Condillac & Perry, 1998).

There are several factors to consider when evaluating treatment effectiveness (Freeman, 1997). Families want the best for their children and it is important to balance their sense of hope with some healthy skepticism. Beware of those who claim to have miracles or cures for all children with autism. Most treatment takes hard work, and there are few easy answers. Because children with autism can be very different from each other, be careful of those who claim to have one "pre-packaged" solution to this very complex problem. Many children with autism require a multi-modal approach that includes several treatment components. With such complex needs, treatments for those with autism should be based upon individual assessment and be specifically tailored to the needs of each child. It is important to be aware of the current debates and beware of the bandwagons. Well-meaning staff and family members, who are trying to act in the best interest of the child can easily be lured. Consider the potential risks and benefits that a treatment may have. While some treatments pose significant health risks, others may result in financial hardship. Also, some untested interventions discourage or take valuable time away from treatments that have empirical support, with little benefit in return. It is essential to consider the evidence and ask potential treatment providers about the types of evidence available to demonstrate the effectiveness of the intervention.

Green (1996) suggested an empirical approach to evaluating the effectiveness of proposed treatments for Autism based upon scientific evidence. She provides an excellent framework to assist parents and professionals in scrutinizing scientific studies. Treatments with demonstrated efficacy would be considered to have less ambiguous evidence than treatments speculated to be helpful. Testimonals of “miracle cures,” while compelling, are not sufficient evidence of effectiveness. Studies that use objective measures of treatment outcome are more convincing than subjective, anecdotal reports. Some objective measures are better than others: direct measurement of developmental and behavioural outcomes (e.g., data collected by an unbiased observer) is considered to be more solid evidence than rating scales completed by those closely involved with the child. Studies that compare progress between different types of intervention or compare the outcomes of those receiving treatments to a those receiving no treatment at all are considered to have more scientific rigour than studies that do not compare effects between groups. Research studies that control for alternate explanations of observed changes leave less doubt about treatment efficacy, and yield important information about the reasons for change, than studies that are uncontrolled.

In summary, there are many treatments which claim to have a positive impact on children with autism; however, many do not have objective evidence to support their use. Given all the claims one can find on the web and elsewhere, it is essential to be an informed consumer.

The National Autistic Society Home Page

http://www.oneworld.org/autism_uk/welcome.html

The home page of the National Autistic Society in the United Kingdom offers considerable information related to autism and intervention. A list of resources and publications covering diverse topics for both families and professionals is available, including links to intervention sites.

The Autism Society of America Home Page

http://www.autism-society.org/

The Autism Society of America Home Page offers a wide range of information and supports for families of children with autism and service-providers. One can find extensive information on early intervention, challenging behaviour, intensive behavioural intervention, medications, diet, and educational interventions, with links to other sources of information.

Centre for the Study of Autism Home Page

http://www.autism.org/

The Centre for the Study of Autism is located in Salem, Oregon. The main page offers some excellent information on autism and links for information on several controversial treatments that have limited scientific evidence. The links page (http://www.autism.com) can connect you to more treatment related sites. The site warns that "information is not intended to be medical advice."

The Recovery Zone Home Page

http://pages.prodigy.net/damianporcari/recovery.htm

This web page is a comprehensive resource of information related to the use of intensive discrete trial training using the principles of applied behaviour analysis. Detailed information related to setting up in-home programming is included.

Teacch Home Page

http://www.autism-info.com/teacch.html

The Treatment and Education for Autistic and Related Communication Handicapped Children (TEACCH) Program is located in North Carolina. Its home page provides an overview of their program and information centred around educational intervention. Topics include communication, toilet training, structured teaching, early intervention, and guidelines for evaluating treatment approaches.

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Information for Authors

Journal on Developmental Disabilities publishes original scholarly work pertaining to the field of developmental disabilities. The goal is to publish articles that increase our knowledge, enourage debate, and have the potential to improve services.

Format

Various formats are acceptable, including: *(a)* original data-based research; *(b)* program evaluation; *(c)* qualitative evaluations; *(d)* program, service, and innovative practice descriptions; *(e)* literature reviews; *(f)* discussion papers; *(g)* conceptual and theoretical papers; *(h)* policy analysis, *(i)* case studies; and *(j)* resource reviews (e.g., books, movies, websites, and software related to developmental disabilities).

Style

For the most part, the manuscript should be prepared according to the *Publication Manual of the American Psychological Association (APA)*, Fourth Edition. The entire manuscript (including tables and references) must be typed and double-spaced, on 8½ × 11" white paper with at least 1" margins around. Titles should be no longer than 15 words. An abstract of not more than 100 words should be included. References must conform to the APA style. Manuscripts should be limited to 2,500 words (not including references and tables, and figures). Footnotes are discouraged. If using word processing software, try to prepare the manuscript to resemble the finished product as it would appear in print (see the articles in this issue for examples). That is, instead of using underlining for emphasis, titles, and statistical notations, use *italics*; create the headings as seen in this issue. If accepted for publication, manuscripts may undergo copyediting prior to printing. Any substantive changes will be cleared by the author before publication. If the manuscript is accepted, you will be asked to submit a word processing file (preferably WordPerfect 6.1 or lower) on 3.5" disk compatible for

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Identification

As the reviewers are not provided with author identification, please remove identifying information from the title page and place it on a separate page. Do not include acknowledgments in the submission if this allows for identification of the authors.

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Please submit 5 high-quality copies of the manuscript. Please include a letter of transmittal in which you indicate that the enclosed manuscript represents your original work and that it has not been published elsewhere or is currently under review, If you wish the manuscript to be considered for the *Mentoring Option*, please indicate so in the cover letter. Send manuscripts to:

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