DOCUMENT RESUME

ED 341 199 EC 300 872

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TITLE Developing Advocacy for Special Needs in an International Community.
PUB DATE Oct 91
NOTE 24p.; Paper presented at the International Conference of the Division of Career Development of CEC (6th, Kansas City, MO, October 9-12, 1991).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Access to Education; *Child Advocacy; Cultural Differences; Definitions; *Disabilities; Family Programs; Foreign Countries; *Global Approach; Organizations (Groups); Parent Associations; Surveys
IDENTIFIERS *Belgium (Brussels); *BRUSH (Belgium)

ABSTRACT

This paper examines issues of special needs advocacy in an international context and describes BRUSH (Brussels Support for the Handicapped), an advocacy organization in Brussels, Belgium. The possibility that advocacy is a culturally determined concept is raised. BRUSH is a group of families from the international community of Brussels who provide advocacy services for English speaking handicapped individuals and their families in the area. The group has surveyed the community, sponsored conferences, and increased its international emphasis. A data collection project utilizing multiple methods (interviews, questionnaires, and document analysis) and multiple sources (national advocacy groups and international groups of parents or professionals) was conducted. Respondents (N=36) were multicultural, multilingual, and multinational and favored advocacy programs primarily for family members and parents. When asked about the nature of international advocacy respondents differed as to its adversarial nature but agreed that fluency in both the maternal and environmental languages is important. The survey also identified the issue of culturally appropriate vocabulary for efforts in international advocacy. Specific issues identified included the confusion over an international definition of advocacy and the high mobility of community members. Includes 18 references. (DB)

DEVELOPING ADVOCACY FOR SPECIAL NEEDS IN AN INTERNATIONAL COMMUNITY

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5043 words excluding Bibliography

ABSTRACT

In both national and international communities, advocacy can be a method to identify and improve the interaction among an individual, a problem, and the environment. However, the word advocacy may be one example of a culturally determined word. There are obvious links between national and international advocacy, but there are also some obvious differences as exemplified by the special needs programmes and services developed by international families who formed BRUSH, an advocacy organization in Brussels, Belgium. To further explore the issue of international advocacy, a small data collection project was planned to collect information from national and international groups to identify and describe any similarities and differences. International data collection involves multiple methods (written, spoken, historic, and current) from multiple sources (multicultural, multilingual, and multinational) in multiple locations (Europe, UK, and US). (132 words)

US Department of Education

Office of Educational Research and Improvement

Educational Resources Information Center (ERIC)

submitted November 1991

Division of Career Development (DCD) of CEC

Sixth International Conference

"Moving into the 21st Century: Meeting the Transition Challenges of Changing Populations"

October 9-12. 1991

Holiday Inn Crowne Plaza, Kansas City, Missouri

Sponsored by the International Division of Career Development of CEC

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INTRODUCTION

Advocacy is "verbal support or argument for a cause or policy," and an advocate is one who favors, pleads, recommends, supports, and suggests on behalf of him/herself, another, or a cause. (Allen 1991) Most experts suggest that advocacy is:

> An active process in which one individual defends or generally supports the rights of another who has any special and personal need for help, and it is an increase in the role of the self-advocate through empowerment of the one needing help. (Anderson 1982, Bancroft 1986, De Leon 1990, Hooevar 1979, and Pasenella 1977)

In both national and international communities, advocacy can be a method to identify and improve the interaction among an individual, a problem, and the environment. (Carson 1988) The processes of advocacy and empowerment is clearly illustrated in American special needs education where parents have been empowered by the law to represent the needs of their children, to encourage self-advocacy in the children to empower them to speak for themselves, and to seel the provision of services not regularly offered by local public agencies, and the legal system became one of their tools for success. (Beazley-Richards 1988, Gearheart 1980, Hansen 1987, Hartwell-Meyers 1978, Moore 1989, and Pederson 1989)

Their activities culminated in the passage in 1978 by the US Congress of the All Handicapped Children's Act (Public Law 94-142), a legal base from which parents and teachers acted with equal rights and responsibilities as advocates.

English parents obtained a legal base when the 1981 Education Act stated they had the right to make their views known and to be involved in the assessment and planning for special needs students. As in the U.S. law, English parents are seen as active participants in education and advocates for children's rights. However, there is a significant distinction. Public Law 94-142 is prescriptive and describes how education must be and defines who will be held accountable for this education. The 1981 Education Act is an enabling statement describing how education may be. Russell (1983) wrote that for English parents to move to the role of active agents in education the voluntary sector would have to advocate for parents' rights. In future, she saw the voluntary agencies as advocates for an entire range of health, education, and welfare services. She said that although US public law had defined the advocacy role for American parents, in England the voluntary sector would have to create "the right to acquire the skill of self-advocacy in order to participate in decision-making processes."

Although there are national advocacy definitions, is there any evidence to assume that advocacy has an international definition? Is it possible that advocacy is one example of a culturally determined word? There are obvious links between national and international advocacy, but there are also obvious differences as exemplified by the programmes and services developed by the international families who formed BRUSH, an advocacy organization in Brussels, Belgium.

BRUSSELS SUPPORT FOR THE HANDICAPPED (BRUSH)

Brussels is the home of the Belgian government, NATO which sponsors a school for military dependents, and the European Community which has a system of schools for employees' children. It is also the headquarters for many multinational businesses and international services. The English-language community in Brussels supports a weekly news magazine, a number of churches, and many private international schools covering pre-school to university. The University of Brussels offers an English-speaking undergraduate programme (Versalius College) in cooperation with Boston University. The Community Help Service, a private professional counseling programme, deals with a wide range of emotional, marital, and learning problems and runs a 24-hour information and crisis phone line. Their English-language services reach a client base estimated at over 30,000. Brussels represents a multicultural, multilingual, and multinational community because it includes multiple populations seeking multiple resources from local, overseas national, and international sources.

BRUSH is an international group because it is neither Belgian nor the country of origin of each of the members but something new and unique to the local multicultural, multilingual, and multinational environment. The BRUSH members are primarily speakers of English who are resident in Brussels but not Belgian nationals. They represent the international community because they have high levels of successive mobility, speak a language other than their maternal language, and are part of multinational families. A psychologist with the Community Help Service, describes this international community as "A group of people who are

trying to set up locally a way of doing certain things in a particular local and national setting. They are trying to meet their needs within the requirements of what is locally suitable. The local cultural conditions and their national experiences provide an extra element to international life."

Brussels Support for the Handicapped developed in the early 1980's when the International School of Brussels opened a special unit with English language physical, educational, and behavioral resources to serve any child of any handicap who could be determined to benefit from some integration (however small) with the regular school programme. The superintendent proposed to enroll children of different disabilities (with the exception of children with serious emotional problems) as long as they had some communication potential in English and could mix with the other enrolled children.

At a general meeting for the school's potential customers, some parents were surprised at the number of other families present. Banding together, they began to meet and established aims for an organization: to provide information and support for families with English-speaking handicapped children in the Brussels area; to act as a pressure group in order to get better facilities and information for the handicapped; and to aim at creating the maximum possibilities for the handicapped via existing organizations. BRUSH opened membership to anyone interested in the problems of English-speaking handicapped people to include Down's syndrome, neurological impairment, cerebral palsy, and deafness. The members planned to publish a newsletter to keep in touch with community activities, to exchange information on local school experiences, and to help others to understand the many

handicaps represented by the members.

The current BRUSH president, describes the original members as typical of the Brussels international community.

> A very mobile population of people who come on two or three year contracts and then have to go somewhere else and slot into another system. These people, if they had children with learning difficulties or handicaps, found it very difficult to just enter their children into the Belgian system because of the language difficulties. Our idea was to act as support for this kind of child and parent. The emphasis in the beginning was on looking at the educational opportunities here and serving as a source of information. We found that a number of people had asked before coming what was available in Brussels and had been told by schools and organizations "Don't come. We can offer nothing. Despite that they did come and despite that they had found some way to deal with the problem.

A founding BRUSH member feels that as pioneers for future Anglophone parents in Brussels the original members tried:

> To help anyone in a similar situation while recognizing that no two cases are alike. Most of us did not choose to come here with a handicapped child. We were stuck here, and we would choose to live our lives here. Some people did move away because the going was rough with the two languages (Belgium is a bilingual country). We thought as a family of moving back to the UK, and we were strongly advised by all the professionals to move back to the UK. We decided to work here with what we had.

A early BRUSH survey of the English-speaking community identified general concern for three issues: integration of children into regular programmes, investigation of local Belgian resources, and provision of assessment for

multilingual/multinational families and children. The group sponsored meetings with internal and external speakers who spoke across handicaps to identify common problems and solutions. By December of 1984, BRUSH had been adopted by local Belgian charity. In 1986, members were invited to participate with teachers and professionals at the European Council of International Schools' conference on Special Education.

Additional recognition of the organization's maturity came with their sponsorship of two conferences. A Seminar on Computers for the Handicapped and Integrated Education for the Disabled. The conferences were remarkable because they gave BRUSH a public profile and put all the international schools together to talk about the questions and problems involved in the special education of 102 identified handicapped/special needs English speaking persons. By 1988, the group discovered that they were no longer just a support group for handicapped children but a support group for handicapped people. They announced WHO CARES?, a project to establish a list of individuals who wished to offer services to special needs individuals and families needing help. BRUSH acted as a contact service to put related needs together. This move brought them into the non-English community.

Not only did the organization grow, but the members found they had changed because of their integration into the international experience. The following quotations from BRUSH members represent the attitudes of individuals who can look across the transition from national culture to international culture, from maternal language to environmental language, and from national education to

international education. Their comments are used to illustrate their personal mobility and the empowerment of each as a self-advocate and an advocate for others. A Brussels-based psychologist describes this empowering process saying, "There is a special kind of social psychology with expatriate people in the sense that they are not immediately part of the local group and must learn to belong."

> MOTHER: I have been out of the UK for 18 years. I do not think you can say it would necessarily have been better if you had never left your national context, but I think being extracted from your national context makes you think internationally. That means you don't look to see what there is in Belgium but across Europe. I am going over the Paris in April to organize special needs learning in English in a French school. Recently, I was called on the phone by the Belgian language center where my children are evaluated. I spoke to a Belgian woman who is living in London who called me up for help. It was the reverse. Here I was a foreigner telling her about her country.

The psychologist continues saying that international persons"have a history of transition from one country to another and carry personal changes with them."

> COUNSELOR: When I return home (what ever that means), I think that the sensitivity and awareness of other cultures will remain. It is not a shock but a revelation that internationally everyone does not think the same way. I have a friend here from Texas who has learned here to be more tolerant. In Texas, there are Mexicans who only speak Spanish. She says she used to be incensed that they did not speak English, but her struggle to learn French at anything other than a basic level has taught her a tolerance she will never lose. She now knows how the people at home feel when struggling with another culture and how difficult it is to learn another language as an adult. The international experience will never leave. You can never go back.

A different Brussels-based psychologist continues the theme of empowerment saying, "All this moving causes you to lose the rigidity of your own culture and makes you more open to what people bring with them. Although the problems on the surface seem the same if the people come from different cultures they recognize that their problems are different."

TEACHER: I have often wondered if I were to start a school right now what educational system I would choose? The answer is that I do not know. Both have positive aspects. For some kid, the tracking system in my national state schools would be very good because of the options and the teaching. For others, the variety of placement in the American system would be of help. Really, a combination of the both would be good. Living in another country is the process of really integrating.

The activity of the BRUSH group opened doors in the local community. One BRUSH parent remembers, "I asked for my kids to be admitted to one local school, and they were turned down. The administrators said, 'Absolutely no!' straight away. I was told that the best thing to do was to send the children away. I think that if I had had BRUSH behind me at that stage we could have probably got them in. That is what BRUSH can now do. It can listen and speak to organizations and with stature say, 'Deal with us.'"

DATA COLLECTION

To further explore the issue of international advocacy, a small data collection project was planned to collect information from national and international groups to identify and describe any similarities and differences. Because of the complexities of multicultural, multilingual, and multinational respondents, international data collection needs multiple methods (written, spoken, historic, and current) from multiple national sources in multiple locations.

MULTIPLE METHODS - Survey methods (interviews and questionnaires) supplemented by document analysis

MULTIPLE SOURCES - A population representing both national advocacy groups (consumer, political, and legal) and groups of international parents or professionals (specialized

experience or knowledge).

Interviews were conducted with English-speaking teachers, counselors, and parents of any nationality who act as self-advocates, advocates, volunteers, professionals, parents, and administrators in national and international settings. Questionnaires were sent to administrators in groups and organizations in the United States, England, and Europe that could be identified in a print source as 'advocating' for the rights of a particular group.

The respondents were primarily US or UK citizens from America, England, Belgium, Italy, and Switzerland. Many of the respondents have not only lived outside their native countries for many years but also lived in many countries. One mobile international respondent said, "I empathize with parents whose kids now have no sense of belonging at home. I had a choice in moving, my children didn't. One child was born in Germany, lived in the US, Belgium, and Holland. The other child was born in the US and is growing up in Belgium." A number of respondents came from multinational families. One respondent described a typical international family as "a German man married to an Italian woman with children born in Strasbourg going to school in Brussels." Additionally, although most of the respondents identified English as their maternal language, they were not asked about their present or previous environmental languages, although it was obvious that many had some mastery of a second or third language.

SUMMARY OF DATA COLLECTION PLAN

Purpose	To compare national and international advocacy. To develop an international definition of advocacy. To identify difficulties in international data collection.
Respondent Focus	Experience with advocacy Personal definition of advocacy Identification of advocacy activities
Method	Interview (Unstructured questions and probes) Questionnaire 46 items (Constructed and selected response) 7 True-False 10 Yes-No 4 Multiple choice 1 Ranking 1 Fill-in set of 23 items with an ordinal scale.
Respondents	Maternal Language English 8 (American/English/Scottish/Irish) Other 1 (Dutch) Nationality American 11 British 23 Other 2

DATA ANALYSIS

The first goal of the analysis was to compare national and international advocacy. Available literature had indicated that they both have multicultural and multilingual populations and that these descriptors affect publications, services, and programme development. National advocacy is supported by national funding and national law, but international advocacy is without state funding and not protected by or accountable to any one law. Additional differences between national and international advocacy include the dependency of national advocacy on the cultural experience of a single nation, while international advocacy must take into account the cultural, linguistic, and experiential differences of many nations. There may also be a discrepancy between the maternal language of the international advocate and the environmental language of the advocacy. Problems are also possible when

advocacy is different from or not known in the native culture A representative international group like BRUSH should unite members from multiple cultures, languages, and nationalities in support of multiple populations seeking services from multiple sources. The data suggests that the primary difference between national and international advocacy is that the international advocacy respondents are a multicultural, multilingual, and multinational group. The data also suggests that another difference between national and international advocacy may be the type of participants. The questionnaire responses favor advocacy programmes primarily for family members and parents (86% of respondents).

The second goal of the analysis was to develop an international definition of advocacy. Questionnaire respondents agreed (60% to 95% of respondents) that advocacy is meaningful participation in educational programmes." They also agreed (60% to 90% of respondents) that "all children have the same rights to education to achieve individual potential; that all and parents children should receive instruction in self-advocacy; that advocacy awareness begins with learning about rights and responsibilities; and that advocacy activities do not lead to segregation but rather encourage greater integration of special needs children into the local community." There was some dissention (agreement from only 50% of respondents) among respondents on whether or not advocacy is an adversarial process. One US respondent expanded this idea saying, "Advocacy should not be adversarial but often is.' A UK respondent continues, "In our country, advocacy is adversarial and political and is based on local government initiative, only recently are national voluntary organizations beginning to promote the non-adversarial idea."

Although respondents suggest that the actions of an advocate may seem the same whether in the national or international community, often performing these actions internationally is very different. International advocacy often demands fluency in a combination of the maternal and environmental languages.

The third goal of the analysis was to identify any unexpected problems in soliciting information from national and international groups. One major difference seemed to be the issue of developing a vocabulary appropriate for a multicultural, multilingual, and multinational set of respondents. The issue of culturally appropriate vocabulary appears on the questionnaire in a set of 23 'risk-taking' activities. Some of these activities appeared to the researcher as 'risky' because they exposed the individual to the chance of criticism or humiliation, to exposure of personal problems, to loss of self-esteem, or to challenge to reputation or credibility. When 50% or more of national and international respondents chose an activity with a ranking of 'very comfortable/comfortable' that activity was accepted as an identifier of an international advocacy activity or an advocate. Two activities (public speaking and writing and seeking legal protection) were selected by less that 50% of respondents. This is understandable in Brussels where writing to a newspaper or speaking at a neighborhood meeting requires fluency in one of the local languages - French or Flemish. Seeking the protection of the local law may not be possible for foreigners. International residents may also find that the requirements of a particular national law have little affect on the provision of or existence of local law. One interview respondent remembers an occasion when the option of going to court was denied to him. "It depends on circumstances. An employer might not allow you to take legal action or complain or as a non-national you were not allowed by the local government to take legal action or complain."

Perhaps, the low responses for these questions is related to the researcher's choice of vocabulary. For example, one question asked about challenging a professional "making mistakes." In the international community, persons from different cultural, linguistic, and national experiences frequently make 'mistakes'. Suppose you are a female special education teacher in an international school. How is your assessment report accepted by the Saudi Arabian father? Does the head nodding of the Indian parent really indicate agreement and understanding? Do you accept or reject an expensive gift from a Japanese parent? Why when you give them permission to use your first name do some parents insist on using your title? A psychologist who has lived in multiple countries and speaks multiple languages and now works with international families counsels that to be successful in understanding the language of the international community one must "be open to different cultures, raise personal sensitivity levels, read about history, take risks, and be daring." Whatever the cultural, linguistic, or national background the international advocates come from, to survive they must make a transition to using the language of the local community.

IDENTIFICATION OF EMERGING ISSUES

A number of issues deserving further exploration emerged from the comments of the respondents. First, there seems to be confusion over an international definition of advocacy. Certain organizations were from their self-descriptions selected for data collection as examples of group advocacy. (Richmond 1990) Yet, an administrator of a national advocacy group said, "I do not understand how the questions relate to the work we do." His organization says its aim is to "recruit,

train, and support volunteer advocates for people in the surrounding area." It defines an advocate as "a friend on a one-to-one basis who looks after that person's rights and interests as if they were the advocate's own." Still, their representative said that he did not see it as an advocacy organization. One UK respondent described this contradiction as cultural because:

> All of these activities are political with a small 'p'. Our organization is suppose to be non-political. However, this country has a very adversarial political system. You are constantly pushing the government in power to make changes in the issues of the day. At the same time, you are pushing the opposition to be a bit more specific in their policy. The party in power represents the status quo and controls the resources and any implied or real criticism is automatically a reflection of the opposition. What happens is that the people will not talk to you if they feel you are critical of the party they believe in. That is the nature of politics in this country.

This response suggests that 'advocacy' is a national word based on national experience and context. One respondent representing the English voice agrees, "It is a very American expression and means giving a legal voice to a concern." Another respondent representing the American voice says, "As an American, I always think advocacy is good, necessary, and constructive." Both these people have lived outside their national countries for many years and yet, both still reflect a national vocabulary and experience. Why? Is it possible that the respondent who earlier related advocacy to the national political process is correct? Does advocacy represent the way children are taught about how to behave in their national political process? Does one style of government teach citizens that they have a responsibility to take care of their own needs and solve their own problems, and voting for politicians is one way of achieving that goal. Does another style of government teach citizens that they have a responsibility to follow the government's plan and let

the government solve problems, and voting for a politician is a way to express a political philosophy but not necessarily solve problems. Further investigation could explore whether these interpretations affect the development of an international definition of advocacy.

A second interpretation of this issue is that the English respondents merely reflect the historical roots of the word advocacy which lie in a relationship to the law. A respondent who is neither British nor American but experienced with both cultures says,

> Advocacy from an American perspective has a greater tendency for people to use legal means to ensure that services are provided. Americans use their courts more and have immediate success through the courts. They have greater experience with class action suits. I think, in European law, we do not have as much experience with class action. I doubt that there is as much legal doctrine accumulated in the common law tradition, and I think the tendency for people to pursue their legal right through the court is less well developed than in the United States.

A European-based psychologist working with the international community proposes that not only national law but national custom provide a subtle distinction between British self-help groups and American advocacy groups.

> Britain is quite rich in self-help groups, but those groups would see themselves as precisely that -- providing help not so much legal services as such or services in the sense that the group becomes a plaintive in a legal action or a class action suit that pushes from the implementation of a statute through the courts. I would see advocacy essentially was a legal service. You are taking the needs of an individual and you are looking at the legal implications or legal means of pursuing those needs. This is distinct from a self-help group which is organizing immediate services which might be anything from babysitting to support groups for parents to starting special classes. I see this as a distinction between support and advocacy.

A final word on defining international advocacy comes from a teacher who works with international families in international schools and reminds us that we never "escape our national experience" and always continue to"draw on contacts from our country of origin."

This statement introduces the second new issue that arises from the respondents' mixture of nationalities and cultural experiences. The English-speaking BRUSH respondents came from Canadian, American, English, Scottish, Irish, and Australian backgrounds, but their national experiences have been assimilated by living in Belgium. International persons bring with them their national perceptions of group organization and individual integration into the local experience. One British parent thinks his response to learning through international experience about other national practices is illustrative of a broadening of a national viewpoint.

> Through advocacy I have learned that there is not a problem unique to one country or one city. The economic situation is not a rosy as we thought and the inner cities are all the same. The third world countries have children who may not get much of an education at all. We have in fact in talking to our European partners heard concern about children in third world countries that are not getting any education as we would understand education. We expand out in most things from our own parochial, rather well-off society and how we deal with that problems to think more and more how we help others.

These successively mobile international families must make frequent transitions among cultures, languages, and nations. Moving is a crisis time for any family. Even moving from one side of a small town to another produces a loss of community roots, geographic security, and personal relationships. The transition

must increase in difficulty when a member of the family has a specific health, emotional, or educational problem. (Jonietz 1988) A Brussels-based parent describes living internationally as "living in an environment subjected to more change and more frequent change. I am not saying that you do not get change in your home country but that it is a slower and more progressive type and you might have a stronger support system. For many international children change is the norm." Another long-time Brussels habitant says, "Yes, just look at the frequency with which people, your friends, come and go. You can be sure that the moment there is a family that you get on really well with (you even can swap kids frequently) they will be transferred to the Orient."

The effect of successive individual mobility on advocacy appears when national changes in custom and practice are integrated into the international community. BRUSH demonstrates that as national education policies have turned towards integration, the integration of special needs students into the local international community has increased. The increased advocacy activity of international families makes the homogeneous international community a microcosm of the real world. BRUSH members work for the educational integration of special needs students into international societies because that reflects what many members want for their national communities in the future. For BRUSH members, integration is an issue involving fundamental individual rights. A BRUSH parent says, "I think we are now seeing people arrive here from towns where there are active and large local organizations and where it has been easier to become active. Parents come and say "Well what is here?" and they assume that something should be here." In Brussels, international families seem to be increasingly aware that their national problems and concerns are not isolated from or different from the problems and

concerns from others in other countries. This idea encourages the development of international advocacy like BRUSH as an outgrowth of national practice and a necessary part of international family life.

CONCLUSION

In special needs education, participants have had to look across subjects or areas to the integration of a whole school education programme. Local educators have had to look across city and state boundaries to build appropriate system wide integrated educational plans. Now, all are offered the challenge of looking across national boundaries to see how others provide for the efficient integration and transition of students. The 1991 World Yearbook of Education offers evidence of a national programme for student transition that developed with the help of international models. (Caccamo 1991) This may be only one of many possible examples of linkage between national and international practices. Special needs professionals know that integration and transition are companions in both a theoretical and real sense. Integration occurs after a transition from one place to another. Transition frequently makes obvious the cultural, linguistic, and national barriers and boundaries individuals set for themselves or allow others to set for them. Integration is the removal of barriers for special needs students in local, national, and international communities. As we move into the 21st century, meeting the needs of pluristic and changing national populations may involve looking beyond local and national boundaries for international ideas and solutions. A transition to a broader theoretical perspective can demonstrate whether groups or nations are allowing integration into a broader view of culture, language, and nationality.

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