

Setting the stage for school health-promoting programmes for Deaf children in Spain

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SUMMARY

Implementing health-promoting programmes for the most excluded and at-risk social groups forms a key part of any efforts to address underserved populations and reduce health inequalities in society. However, many at-risk children, particularly children in Deaf communities, are not reached, or are poorly served, by health-promoting programmes within the school setting. This is so because schools are effective as health-promoting environments for d/Deaf children only to the extent that they properly address their unique communication needs and ensure they are both able and enabled to learn in a communication-rich and supportive psycho-social environment. This article examines how the usually separate strands of school health promotion and d/Deaf education might be woven together and illustrates research with Deaf community members that involves them and gives their perspective. The primary objective of this study was to map Deaf pilot bilingual education programmes in Spain—one of the first countries to ratify the Convention on the Rights of Persons with Disabilities (United

Nations. (2006) Convention on the Rights of Persons with Disabilities, Resolution A/RES/61/106.)—with particular attention to their compliance to the Convention's article 24. Following pre-testing, 516 key informants were surveyed by mail (response rate: 42.08%) by using a snowball key-informant approach, within a Participatory Action Research framework, at a national, regional and local level. The results show that although some schools have achieved recommended standards, bilingual programmes are in various stages of formulation and implementation and are far from being equally distributed across the country, with only four regions concentrating more than 70% of these practices. This uneven geographical distribution of programmes probably reflects more basic differences in the priority given by regions, provinces, and municipalities to the Deaf community's needs and rights as an important policy objective and may reinforce or widen inequalities by favouring or discriminating rather than achieving access and equity for this noticeably overlooked community.

Key words: school health promotion; deaf children; human rights; community participation

INTRODUCTION

The Convention on the Rights of Persons with Disabilities (UN, 2006 article 25) states that 'States Parties recognize that persons with disabilities have the right to the enjoyment of

the highest attainable standard of health without discrimination on the basis of disability'. However, all too often persons with disabilities are denied equal rights and equal opportunities to participate fully in every aspect of society, including education, employment, services,

communication and political and social life (Michailakis, 1997; Quinn and Degener, 2002), and therefore have a much poorer chance of achieving their full health potential, a reflection of the widely recognized strong association which exists between inequalities in health status and social inequities (WHO Task Force and the WHO Equity Team, 2005). For the most disadvantaged and vulnerable groups in society, whose exclusion has increased in our globalized world (WHO, 2005), social inequities begin in early childhood. According to UN estimates, the figure of people with disabilities in the world is over 600 million, 150 million of them being at-risk children.

The school is the most important community setting for promoting health among children, school personnel, families and the community (WHO, 1999; Konu and Rimpelä, 2002). Likewise, much is known today about the inextricably and widely accepted relationship between education and health and the social and economic benefits of investing in children's health and education (Burgher, *et al.*, 1999; UNESCO, 2004; Tang *et al.*, 2005; Belli, *et al.*, 2005). In the past decade, a number of international efforts guided by the worldwide policies of 'Health for all' and 'Education for all' have been developed to promote health and education for all learners through schools (WHO, 1999; Burgher, *et al.*, 1999; Jensen and Simovska, 2002). WHO'S Global School Health Initiative and FRESH (Focusing Resources on Effective School Health): A FRESH Start to Improving the Quality and Equity of Education—an inter-agency initiative by WHO, UNICEF, UNESCO and the World Bank—are the most recent ones. Two characteristics shared by each of these initiatives are (i) the role of the school in enabling pupils, staff and the community it serves to take action for a healthier life, school and society and (ii) the importance of a healthy psycho-social environment in schools. Likewise, there is a growing consensus that developing empowerment and action competencies among learners can only be achieved if they are enabled to actively participate in the total life of the school, their family and their community. However, one precondition for participation is that learners should be able to openly express their feelings, views and opinions in their first, preferred or natural language and that they should be able to do so in an enabling psycho-social environment (People's Communication Charter, World Association for

Christian Communication, and Institute of Social Studies, 1999; UNICEF, 2000; WHO, 2003).

However, many at-risk children, particularly Deaf children [lowercase 'deaf' is used to refer to the audiological condition of not hearing, while uppercase 'Deaf' reflects identification with the Deaf community, i.e. a particular group of people who share a common language and culture (also known as the social/linguistic/cultural view of deafness) (Padden and Humphries, 1988; Munoz-Baell and Ruiz, 2000)], have historically been deprived of this prerequisite for developing their action competence by being denied the possibility, both inside and outside educational settings, of learning and using their natural and often only language, sign language (Jacobsson and Akerström, 1997; Kyle and Allsop, 1998; Muth *et al.*, 1998; Vernon and Daigle-King, 1999; Clowes, 2000; Bergmann and Ravn, 2000; Berbrier, 2002; Siegel, 2002). In seeking to redress this situation which is seen as a gross violation of a basic fundamental right of Deaf communities worldwide, over the past two decades many international declarations, recommendations and actions have called for the legal recognition of sign languages and education in sign languages. The Convention on the Rights of Persons with Disabilities (UN, 2006) is the most recent of these. The Convention's article 24 states that 'States Parties shall take appropriate measures, including: [...] b. Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community. c. Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf-blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers with disabilities, who are qualified in sign language and/or Braille'.

For over three decades, many schools have been developing and implementing an educational model for Deaf children, called Deaf bilingual-bicultural (DBiBi) model, which is consistent with the Convention's recognition of Deaf communities' linguistic identity and its promotion of a supportive and fully-accessible school environment. DBiBi programmes have grown in popularity and expanded rapidly all over the world with the support of the United Nations, UNESCO, UNICEF, the World Federation of the Deaf, the European Union, the European

Union of the Deaf and the European Society for Mental Health and Deafness as well as educators, parental organizations and researchers as a model for school Deaf education. In all respects, schools with DBiBi programmes can be seen as healthy and inclusive schools for Deaf children and can pave the way for the development of strategies to implement and institutionalize school health-promoting programmes for the Deaf communities (Table 1). Essentially, DBiBi practices focus on removing major barriers—linguistic, educational, socioeconomic, physical and cultural—Deaf children experience when they enter school. For example, many Deaf children have never met a Deaf adult and often wonder what would happen when they grow up; some of them believe they will become hearing (all adults around them are hearing), some others believe they will die (there are no Deaf adults). Also, because they cannot hear, many Deaf children are convinced that they are less intelligent than the rest of the children, will not be able to learn things as their classmates do, will never get a job (only hearing people get jobs), have children (only hearing people have) or get married (nobody wants to get married with a Deaf person). Accessing basic health information, for example on healthy eating, regular physical activity, human sexuality, AIDS prevention, emotional well-being or healthy environments, becomes a major challenge for Deaf children in a monolingual mainstream school since in this setting they are always surrounded by hearing people who cannot communicate effectively and accurately with them: their teachers and other school staff, peers, parents, health care providers and the wider community. By involving free communication, knowledge accessible through an effective communication tool (sign language), Deaf role models, acceptance by others, and a supportive psycho-social environment, schools with DBiBi programmes have an underlying strength in empowering Deaf children, and by doing so improving the chances of reaching these children, influencing their health behaviours and reducing health risks of Deaf community members. In other words, DBiBi programmes provide a natural setting already opened up to us by prevailing school practices on which to build strategies for health promotion for Deaf children, staff and the wider community.

Yet with the exception of LaSasso and Lollis' study in 1999 (LaSasso and Lollis, 2003) of

residential and day schools for d/Deaf and hard-of-hearing students which described themselves as bilingual–bicultural in the United States, to the best of our knowledge no studies have yet investigated the size and differentials in Deaf bilingual initiatives at the national level, except in those few developed countries where d/Deaf students are not educated in the mainstream education system (Davies, 1991; Foster *et al.*, 2003; Haualand *et al.*, 2003; Meijer *et al.*, 2003). Systematic empirical investigations of the bilingual educational provision for Deaf children typically face formidable challenges. In addition to difficulties in identifying and accessing members of the Deaf communities (mainly, unreliable statistics, distrust of outsiders, poor literacy skills and low response rates) which are common to other areas of research on this and other marginalized populations (Preston, 1995; Jacobsson and Akerström, 1997), there are other important limitations related to the diversity of spoken language-based sign communication systems used by teachers in the classroom, and a large number and differing viewpoints of interested parties engaged in the education of d/Deaf children (Woodward and Allen, 1987, 1988; Christensen, 1989; Hadadian *et al.*, 1997; Kyle and Allsop, 1998; Chisholm, *et al.*, 1998; Foster *et al.*, 2003; Munoz-Baell *et al.*, 2008). Nevertheless, obtaining reliable data on the size, distribution and characteristics of bilingual school experiences for Deaf children can provide a strategic framework for the development, implementation and evaluation of school health-promoting programmes for Deaf communities in and across countries.

A number of previous studies have shown that key informant surveys are powerful tools in planning and evaluating community health programs (Eyler *et al.*, 1999) and that participatory research is useful and more ethical in both analysing social problems that are novel and understudied and gaining the involvement of under-represented and vulnerable populations as well as improving their self-reliance and empowering them; in particular, people with disabilities (Oliver, 1992; Moore *et al.*, 1998; Bricher, 2000; Kitchin, 2000; Enabling Education Network [EENET], 2005; Obinna *et al.*, 2005). Likewise, in line with various international recommendations for actively involving organizations of people with disabilities in research to ensure both that their perspectives are fully taken into account and that decisions are not taken by others (UN, 1993; UNESCO, 1994), a

Table 1: Three different labels grounded in a common key purpose

Issues	WHO Health-promoting school	UNESCO Inclusive school	Deaf bilingual–bicultural school*
Birth of the concept	Built on the collaborative work done in the 1980s under the CE pilot project 'Education for Health'	Was launched at the UNESCO <i>World Conference on Education for All</i> in 1990	Was born in the early 80s in the Scandinavian countries
Arises from	An increasing recognition that health and educational outcomes are inextricably linked, and that the school can be an ideal setting through which to strive for both	Out of concerns about the exclusion of millions of marginalized children, particularly children with disabilities, from education, international efforts to ensure the rights of all children to receive basic and quality education, and the failure of existing institutions and traditional services to deliver education services in ways that meet the needs of those they are meant to serve	The failure of d/Deaf education to significantly improve the achievement of d/Deaf and hard-of-hearing students and an increasing recognition that current Deaf education programmes do not respect the needs or the human, linguistic and educational rights of Deaf children as supported by several international policy statements, conventions and recommendations: the right to full and equal access to quality education, to acquire full mastery of their sign language as their 'mother tongue' as well as to learn the language(s) used by their family and community, and to have access to qualified professionals and adult role models fluent in sign language in a totally supportive, signing and student-centred environment
Growth	It has grown in popularity so that it is now a widely accepted model for school health education	It has evolved from often only referring to 'mainstreaming' to be also concerned with identifying and overcoming all barriers to effective, continuous and quality participation in education, particularly during the primary cycle, where a well-documented human right to free participation is widely accepted	During the last two decades, bilingualism in Deaf education has spread rapidly in many countries, especially in Scandinavian countries and the USA
Definition	A health-promoting school can be characterized as a school which is constantly strengthening its capacity as a healthy setting for living, learning and working and aims to enable pupils, staff and the community it serves to take action for a healthier life, school and society	An inclusive school can be characterized as a school open to ALL children (including those with physical, sensory, intellectual or situational impairments), continually exploring new ways of developing responses that value their diversity and willing to restructure the school's programme in response to the needs of all pupils by identifying any barriers (attitudes, environment, policies, practices and resources) within and around the school that hinder effective, continuous and quality learning and participation in all aspects of school life, and reducing or removing these barriers so that ALL children have the opportunity to gain the knowledge and develop the values, attitudes and skills that will enable them to develop their capacities to work, to participate fully in society, to take control of their own lives and to continue learning	A bilingual–bicultural school can be characterized as a school which aims to reflect the reality of how Deaf youth and adults live in a majority society that includes a Deaf community by creating a bilingual–bicultural environment in which Deaf children can develop early bilingual–bicultural skills through the acquisition and use of at least two languages (a sign language as their first or natural language and a spoken language as their second language) as well as two broad cultures (Deaf culture and hearing culture) as integral aspects of the curriculum and the environment in order to maximize the children's potential to take ownership of their own lives, to develop themselves to the full and to participate fully in both the Deaf community and society as a whole

Table 1: *Continued*

Issues	WHO Health-promoting school	UNESCO Inclusive school	Deaf bilingual–bicultural school*
Ethical dimension	Health and education are viewed as fundamental human rights for all children	Education and participation are viewed as fundamental human rights for all children	Access to information and communication using their natural language are viewed as fundamental human rights for all children and preconditions for equal participation in all spheres of society
Draws on the values of	Democratization, social justice and human rights	Democratization, social justice and human rights	Democratization, social justice and human rights
Based on	A social model of health. This includes not only the person, but the person in his or her environment, and therefore strives to build health into all aspects of life at school and in the community	A holistic view of education and a social model of disability by looking at disabilities and learning difficulties from the point of view of interaction between the learner and the environment and resulting from barriers to access created by discriminatory attitudes, actions, cultures, policies and institutional practices which should be identified and dismantled to enable and empower all persons to fully and equally participate in the life of the community	A socio-cultural view of deafness. It sees the Deaf as a sociocultural minority ('different' but not deficient) with a distinct history, unique values, a heritage, a culture and especially a language which shares characteristics with other minorities. The problems the Deaf face result from discriminating conditions in society
Joint action	Stresses the importance of both pupils' participation, parents and the nature of interaction between the school and the community it serves	Promotes partnership and participatory approaches to learning and teaching, encouraging learners and teachers to work collaboratively, and opens doors to the active involvement of parents, organizations of persons with disabilities and communities	Works on the basis of partnership among parents, students, school and the Deaf community and collaboration with researchers
Implementation	It requires a transformation of traditional approaches to the provision of education, and to teaching and learning, and a revolution in training for the education profession. It also requires a pedagogical and attitudinal change and attention, not only to the structure of schools and classrooms, but also to the circumambient conditions that facilitate learning for all, both inside and outside learning centres, as well as the development and sustenance of creative partnerships, involving both intersectoral and interprofessional co-ordination and co-operation		

*Information contained in the third column of this table, in agreement with the proposal of the World Federation of the Deaf for Deaf bilingual programmes, tries to synthesize basic and common tenets of this educational approach.

variety of studies have pointed out that disability-related research which does not involve people with disabilities makes no contribution and can even be detrimental to the lives of disabled people (Werner 1987; Oliver 1992; Stubbs, 1995; French and Swain, 2004) and more specifically that research in the field of d/Deaf education too often furthers the discrimination and oppression of Deaf people (Lane, 1992; EENET, n.d.; Evans, 2004). Accordingly, the primary aim of the research being reported here was to map Deaf bilingual pilot experiences in Spain—one of the first countries to ratify the Convention on the Rights of Persons with

Disabilities (UN, 2006)—with particular attention to their compliance to its article 24 target by using a snowball expanded key informant approach at a national, regional and local level, within a Participatory Action Research framework, which involved working in close partnership with the Deaf community.

METHODS

Involvement by Deaf community stakeholders

The Deaf community is a highly interactive and geographically dispersed minority in Spanish

society. Deaf community members are represented by a non-profit and politically active NGO of social action established in 1936 which comprises 135 organizations spread all over the country, with one member Federation per Autonomous Region, and at least one association of Deaf people in the 96% of the provincial capital cities. Like other Deaf communities all over the world, the Spanish Deaf community consists of very diverse and heterogeneous individuals who share common values, beliefs, customs and heritage and most importantly two legally recognized sign languages with several regional dialects. Central to the concept and concerns of Deaf community members has always been their educational provision, which makes them particularly important for ensuring that consistent information on bilingual provision is collected. Accordingly, the first phase of the project involved making contact with their national umbrella organization (CNSE). As a result, an advisory group of Deaf community stakeholders was incorporated into the research team. The advisory group and the research team met regularly with the aid of sign language interpreters to provide direction to the research process from a Deaf community perspective, and to incorporate feedback and lessons learned back into the research design, the process and the data analysis. Working definitions of health, health promotion, health-promoting schools, Deaf community issues, Deaf bilingual education and participatory research were discussed and agreed upon early in the research process and revisited at several stages of the project.

Setting

Spain has a population of 45 117 million inhabitants (2007 census) and is divided into 17 Autonomous Regions and the Autonomous Cities of Ceuta and Melilla, each with separate governmental structures, degrees of autonomy, co-official languages and/or dialects and different cultural backgrounds. In the field of education, the Autonomous Regions have the autonomy to develop regulations from a legislative viewpoint regarding the non-basic elements of the education system. In addition, they have executive and managerial powers which allow them to administer the education system according to the socio-political context of their own territory. People with hearing loss

represent approximately 2.22% of the Spanish population, but the size of the Spanish Deaf community is difficult to measure. Estimates range between 19 436 (Kyle and Allsop, 1998) and 92 787 (Amate, 2001). Estimates of the size of Deaf communities or Deaf populations may differ to a great extent depending on whether numbers include only: (i) Deaf and hard-of-hearing individuals who share a common language and culture; (ii) people with a severe-to-profound hearing loss; (iii) people who are profoundly and prelingually deaf; (iv) 'early-deafened' population—regardless of the origin, degree or type of loss—who have experienced childhood and adulthood within the Deaf community rather than the hearing community; or (v) sign language users, whether deaf, hard-of-hearing or hearing—whose social lives are deeply involved with other signing people. Following the current tendency in the European Union and many other countries around the world towards a mainstream policy of the incorporation of pupils with special educational needs into regular schools, and through special needs reform in the early 80s, the Spanish government developed a one-track policy approach geared towards the integration of almost all pupils—including d/Deaf and hard-of-hearing pupils—into the regular education system (Meijer, 2003; Meijer *et al.*, 2003). This mainstream policy has gone hand-in-hand with the tradition, strongly rooted in Spain, of choosing only spoken languages for the instruction (also called 'oral education') of d/Deaf and hard-of-hearing children. Very recently, but not yet at the time of the study, and following intense lobbying from the international and national Deaf organizations, the sign languages of Spain and Deaf children's right to a bilingual education have been legally recognized. In the meantime, Spain's bilingual education practices for the Deaf have functioned on a voluntary, experimental basis with limited funding and often with opposition from some parents, educators and educational authorities.

Target population

In the absence of official registers of community members and stakeholders likely to be knowledgeable about d/Deaf education at the national, regional and local levels, we considered three ways of identifying and reaching key informants. The first was to use information

Table 2: Breakdown of key informants by stakeholder group and geographical scope

Stakeholder group/perspective	Number of key informants	National <i>n</i> (%)	Regional (autonomous regions) <i>n</i> (%)	Local (municipalities and provinces) <i>n</i> (%)
d/Deaf people organizations	110	3 (2.7)	17 (15.5)	90 (81.8)
Associations of parents of d/Deaf children	76	1 (1.3)	11 (14.5)	64 (84.2)
Schools known to cater for d/Deaf children ^a	68			68 (100)
Educational professionals' associations	50	4 (8)	13 (26)	33 (66)
National and regional government administrations	197	6 (3)	36 (18.3)	155 (78.7)
Experts ^b	15			15 (100)
Overall total	516	14 (2.7)	77 (14.9)	425 (82.4)

^aAlthough a nationwide register of mainstream schools was available at the time of the study, we included in the sample only schools we did know to be serving d/Deaf and hard-of-hearing children. The remaining schools were omitted from the sample for reasons of cost and data reliability.

^bExperts included university researchers with expertise in Deaf studies and a few professionals in specific Deaf-related service areas who would not be reached through the other defined groups.

from a series of sources, including the network of the CNSE, consultation with national organizations involved in d/Deaf education, literature searches and the Internet. The second was to encourage respondents of the questionnaire to refer individuals to the study and/or ask other interested key individuals to complete the same questionnaire (a copy of it had been previously sent to each key informant for the purpose of facilitating its hand-delivery and return to us), and the third was to post the questionnaire on the Internet. The characterization of the groups was more difficult than expected and had to be altered as a result of preliminary discussion within the expanded research team. Eventually, we defined 6 groups and 16 subgroups for the purpose of ensuring good cross-section and inter-group comparisons. Defined groups were as follows: (i) d/Deaf people organizations, (ii) associations of parents of d/Deaf children, (iii) schools known to cater for d/Deaf children, (iv) educational professionals' associations, (v) national and regional government administrations and (vi) experts (Table 2). Groups were chosen for the following reasons: first, gaining information from different groups would give a more global and comprehensive picture of what is occurring within the school site. Second, the groups appeared to have their own 'stake' in the school and their own unique perspective on the research question. Third, gaining information from representatives of separate major groups of community stakeholders might help initiate (or strengthen) the lines of communication among them and give members several different

avenues to approach Deaf educational policy in their communities and bring about change. For these reasons and as a result of the Spanish devolution process in educational administration mentioned above, efforts were made to ensure that the sample covered all parts of the country and was evenly distributed across all six sets of informants, though not every autonomous region had representatives of all groups (Tables 2 and 3). Once the final list was compiled, names and addresses of individual key informants were obtained by using the network of the CNSE, area telephone books, literature searches and the Internet. Also, calls were made to verify addresses and identify the names of addressees in order to personalize cover letters as far as possible.

Key informant survey development and data collection process

One initial decisional discussion focused on the development of a key informant questionnaire accessible to both Deaf and hearing communities' participants in their first languages. We also discussed the possibility of producing the questionnaire in both Spanish sign language and Spanish. However, we decided that this would have been a very resource- and time-consuming way to conduct the survey and chose to produce a self-administered six-page paper-and-pencil questionnaire in a Deaf-friendly format requiring approximately 15 min to complete, along with an electronic version of the questionnaire as an alternative response format. Questions

Table 3: Number and distribution of key informants by targeted group and autonomous regions

Autonomous Regions	Stakeholder groups						TOTAL <i>n</i> (%)
	d/Deaf people's organizations <i>n</i> (%)	Associations of parents of d/Deaf children <i>n</i> (%)	Schools known to cater for d/Deaf children <i>n</i> (%)	Educational professionals associations <i>n</i> (%)	National and regional government administrations <i>n</i> (%)	Experts <i>n</i> (%)	
Andalucia	16 (15)	16 (21.4)	6 (8.8)	11 (23.9)	11 (5.8)	4 (26.7)	64 (12.7)
Aragon	1 (0.9)	4 (5.3)	5 (7.4)		25 (13.1)		35 (7)
Asturias	5 (4.7)	2 (2.7)	1 (1.5)	2 (4.3)	3 (1.6)		13 (2.6)
Balearic Islands	3 (2.8)	1 (1.3)	6 (8.8)		15 (7.8)		25 (5)
Canary Islands	4 (3.8)	8 (10.7)	1 (1.5)	1 (2.2)	13 (6.8)	1 (6.7)	28 (5.6)
Cantabria	3 (2.8)	1 (1.3)	2 (2.9)		10 (5.2)		16 (3.2)
Castilla & Leon	10 (9.4)	6 (8)	5 (7.4)	3 (6.5)	24 (12.6)		48 (9.6)
Castilla-La Mancha	7 (6.5)	6 (8)	1 (1.5)	1 (2.2)	14 (7.3)		29 (5.8)
Catalonia	12 (11.2)	4 (5.3)	3 (4.4)	5 (10.9)	17 (8.9)	2 (13.3)	43 (8.5)
Valencian Community	13 (12.2)	5 (6.7)	2 (2.9)	3 (6.5)	10 (5.2)	2 (13.3)	35 (7)
Extremadura	3 (2.8)	3 (4)	2 (2.9)	1 (2.2)	7 (3.7)		16 (3.2)
Galicia	7 (6.5)	3 (4)	13 (19.1)	5 (10.9)	6 (3.1)	4 (26.7)	38 (7.5)
Madrid	8 (7.5)	10 (13.3)	4 (5.9)	9 (19.6)	10 (5.2)	1 (6.7)	42 (8.3)
Murcia	6 (5.6)	2 (2.7)	15 (22)	2 (4.3)	4 (2.1)		29 (5.8)
Navarra	1 (0.9)	1 (1.3)	1 (1.5)		3 (1.6)		6 (1.2)
Basque Country	6 (5.6)	2 (2.7)	1 (1.5)	3 (6.5)	7 (3.7)	1 (6.7)	20 (4)
Rioja	1 (0.9)				7 (3.7)		8 (1.6)
Ceuta		1 (1.3)			2 (1)		3 (0.6)
Melilla	1 (0.9)				3 (1.6)		4 (0.8)
Total	107 (100)	75 (100)	68 (100)	46 (100)	191 (100)	15 (100)	502 (100)

Table 4: Research procedures and response rates across stages of the survey

	Initial mailing	Second mailing	Pilot telephone follow-up	Telephone reminders and third mailing	Total
Timing (2003–2004)	1 September–29 September	30 October–25 November	8 January–30 January	10 February–30 February	
Population surveyed	516	438	31	131	516
Mail returned with address unknown	7	8	1	1	17
Adjusted population surveyed	509	430	30	130	499
Responding non-respondents	6	20	6	6	39
Completed questionnaires received	83	91	12	24	210
Completes					
Returned by mail	40	40	8	5	93
Returned by fax	33	24	1	8	66
Returned by e-mail	10	27	3	11	51
Response rate (%)	16.30	21.16	40	18.46	42.08

were developed by the expanded research team around two broad areas of interest and were limited only to a mapping of bilingual provision in primary education (pupils from 6 to 12 years old). Respondents were asked to name schools in which, apart from the official language/s of their autonomous region, a sign language was used as a means of communication with d/Deaf and hard-of-hearing children, and to provide contact information. They were also asked to inform if Deaf people worked in the school, if the local Deaf community was collaborating with the school in this programme, and to indicate the stage of development of the bilingual experience. Findings from a series of additional questions trying to document when, by whom, how and why pilot bilingual programmes had been initiated at schools will be reported in a further paper.

The questionnaire was initially pretested with a sample of key informants from each targeted group. The emphasis was on simplicity of style to ensure that questions could be easily understood by our intended audience, particularly by Deaf community members. After pre-test results were collected and analysed, suggested modifications to the questionnaire were made. Lastly, postal questionnaires were sent out to a total of 516 key informants along with an extra copy of the questionnaire and a covering letter explaining the aim of the study, providing directions for completion and return and assuring participants that responses would be kept confidential. After the initial responses to the survey were received, a second copy of the survey was mailed to those who had not yet responded.

Additional follow-up was done by the CNSE among Deaf non-respondents by means of a supporting letter and reminder phone calls. After the second mailing, pilot phone calls ($n = 31$) were made to test the worth of this procedure in terms of cost-effectiveness and reminder phone calls and third mailings were made to non-responders whose contact phone number was obtainable. All reminders included replacement questionnaires. The entire process culminated with thank-you letters to all respondents.

RESULTS

The data were collected in the period from September 2003 to February 2004, and much of the information relates to practices in place during these years. Responses of some sort were received from 249 informants giving a gross response rate of 48.25% (249/516). Thirty-nine respondents (mostly from the national and regional government administrations group) gave reasons for not completing the survey, yielding 210 questionnaires containing usable data and an effective response rate of 42.08%. Table 4 presents research procedures and response rates to the total number of contacts.

Of the 210 completed questionnaires, 20 (9.52%) were returned anonymously, but postal, fax or e-mail identifying information for 12 of them yielded intergroup comparisons for variations in response rates as follows: d/Deaf people organizations, 45.71%; associations of parents of d/Deaf children, 36.84%; schools known to cater for d/Deaf children, 47.61%;

Table 5: Survey participation by groups of key informants and variations in final response rates between respondent groups and subgroups

Stakeholder groups and subgroups	Total number of key informants	Completes	% of total ^a
d/Deaf people organizations	110	48	45.71
Associations of parents of d/Deaf children	76	28	36.84
Schools known to cater for d/Deaf children	68	30	47.61
Educational professionals' associations	50	26	52
Language communication pathologists	4	1	25
Teachers of d/Deaf children	1		0
Teachers specialized in Hearing and Language support	2	1	50
Spanish Sign Language Interpreters	36	24	66.66
Psychologists	1		0
Deaf sign language advisors	6		0
National and regional government administrations	197	54	27.97
Reporting to the Ministry of Education and Science (MEC)			
Specialized Specific Teams attending hearing-impaired students	18	7	41.17
MEC administrations at national and regional levels	79	23	29.11
State School Council and Regional School Councils	18	2	11.11
Teacher Training and Resource Institutions (CPRs)	37	7	20
National Institute for Professional Qualifications (INCUAL)	1		0
National Institute of Evaluation and Quality of the Education System (INECSE)	1	2	200
University Guidance Units for Students with Disabilities	20	6	30
Reporting to the Ministry of Social Affairs (MTAS)			
Early Intervention Teams	21	6	30
Institute of Migrations and Social Services (IMSERSO)	1		0
Royal Body for the Prevention and Care of People with Disabilities	1	1	100
Experts	15	14	93.33
Origin unknown		2	
Anonymous		8	
Total	516	210	42.08

^aThe population surveyed has been adjusted for the incorrect address returns.

educational professionals' associations, 52%; national and regional government administrations, 27.97%; and experts, 93.33% (Table 5). Among the more interesting differences in final response rate between subgroups is to note that response rate was significantly higher among professional associations of Spanish sign language interpreters (66.66%), associations of teachers specialized in hearing and language support (50%), and associations of language communication pathologists (25%) as compared with associations of teachers of d/Deaf children (0%), psychologists' associations (0%) and Deaf sign language advisors (0%). Also, interestingly we observed no overall noticeably difference in final response rate between national and regional government administrations reporting to the Ministry of Education and Science (30.43%) and those reporting to the Ministry of Social Affairs (27.01%). This suggests that both government administrations felt similarly about the questionnaire's relevance to their work. The

respondents were spread throughout the country with larger numbers in the South (Andalucia, $n = 30$), North-West (Galicia, $n = 19$), East (Catalonia, $n = 14$ and Valencian Community, $n = 14$) and centre (Castilla & Leon, $n = 22$; Madrid, $n = 14$; and Castilla-La Mancha, $n = 13$) of Spain. No questionnaires were returned from Ceuta or from Melilla.

We identified a total of 111 schools (0.79% of the total number of schools which provide primary education in Spain) using a sign language as a means of communication with d/Deaf and hard-of-hearing students spread over all the Spanish Autonomous Regions except for La Rioja, Ceuta and Melilla. Overall, 68 different schools were reported by our first informant group, i.e. d/Deaf people organizations; 38 schools were identified by our second informant group, i.e. associations of parents of d/Deaf children; 25 by schools known to cater for d/Deaf children, 45 by educational professionals' associations (44 of them by associations of Spanish

sign language interpreters); 37 by national and regional government administrations (MEC administrations at national and regional levels, 22; specialized specific teams attending hearing-impaired students, 10; university guidance units for students with disability, 3; teacher training and resource institutions, 3; early intervention teams, 2; and state school council and regional school councils, 1); and lastly 16 schools by experts. Duplicated schools by different informants were removed from the final list.

Analysis of cross-informant data for concordance revealed strong cross-informant agreement (between 12 and 6 informants nominating the same primary school as being using a sign language as a means of communication with d/Deaf and hard-of-hearing students) in 8 different schools. Moderate agreement (between 4 and 3 informants) was found in 31 schools and low agreement (between 2 and 1 informants) regarding the remaining 72 identified schools.

The returns show that although some schools are achieving the UN Convention's recommended standards—sign language learning, recognition of Deaf communities' linguistic identity, promotion of a supportive and fully-accessible school environment and hiring of Deaf teachers qualified in sign languages—, most of them are still at a preliminary stage of formulating and implementing DBiBi educational programmes. In particular, the questionnaire responses reported that only 30 schools (27.03%) use sign language as a means of communication with d/Deaf and hard-of-hearing children, have Deaf role models working in the school, collaborate with the local Deaf community and have more than 1 year's experience; only 43 (38.73%) satisfy three of these conditions, and 38 (34.23%) fulfil only two of them.

We also found that the practice of these experimental bilingual experiences varies greatly across the autonomous regions and is not equally distributed across all regions. Indeed, of the 30 schools which satisfied the basic recommended standards, 4 autonomous regions concentrate more than 70% of these practices, meaning that the majority of Spanish Deaf children still have no access to an equitable education within reasonable distances from their homes (Table 6). Sixty-three of these schools (56.76%) were reported to be located in the provincial capitals compared with 48 (43.24%) in smaller towns and municipalities.

DISCUSSION

It is widely recognized that Deaf community members are a misunderstood and long-under-served minority with unique communication needs and that education is virtually non-existent unless it is accessible to all children through spontaneous and meaningful communication which in turn is not only a basic fundamental right but also one of the preconditions for the development of empowerment and action competence for a healthier life, school and society. Nonetheless, while current health-promoting programmes for schoolchildren undoubtedly benefit many children, they fail to address one of the most basic needs and rights of many minority children; in particular Deaf children, by taking for granted that all children have full access to at least the language spoken by their parents and hence have the means to fully communicate with and understand peers and staff when they enter school (Rinne, 1996; Fiedler, 2001; Quinn and Degener, 2002; Siegel, 2002; Evans, 2004). If addressing long-excluded groups and communities in the settings in which they live, work and play is key for health promotion attempts to ensure equity and school health-promoting initiatives are committed to improving the health of ALL pupils, then language and communication issues should be explicitly acknowledged and given a central role in health-promoting initiatives for Deaf schoolchildren when they are planned and put into practice. The findings of this portion of the project provide an overall picture of a communication-rich educational provision which can facilitate the development of useful indicators of effective school health-promoting environments for Deaf communities in full compliance with the recent UN Convention on the Rights of Persons with Disabilities in and across countries. We propose that the status of sign language, stage of development of the bilingual experience at the school site, and participation of Deaf teachers and Deaf community members in the educational process should be considered as benchmarks to evaluate the situation currently prevalent in and across countries and as the basis for planning health-promoting school initiatives for Deaf children.

Because research into the extent of bilingual educational provision of the target group is still limited and PAR approaches encompass an iterative process that includes on-going learning,

Table 6: Number and location of schools that use a sign language as a means of communication with d/Deaf and hard-of-hearing children as identified by key informants in Spain in relation to other demographic features

Autonomous regions	Total Pop. (2004 census)	Profoundly Deaf population ^a	Number of schools which provide primary education ^b	Schools using a sign language as a means of communication with Deaf children	Schools in compliance with at least three recommended standards ^c	Only 2 rec. standards	Only 1 rec. standard
Andalucia	7 687 518	7687	2564	29	10	5	14
Aragon	1 249 584	1249	382	9	1	4	4
Asturias	1 073 761	1073	332	1	1	0	0
Balearic Islands	955 045	955	294	6	1	2	3
Canary Islands	1 915 540	1915	797	20	0	20	0
Cantabria	554 784	555	211	3	1	0	2
Castilla & Leon	2 493 918	2494	891	3	0	0	3
Castilla-La Mancha	1 848 881	1849	780	3	0	1	2
Catalonia	6 813 319	6813	2202	6	3	0	3
Valencian Community	4 543 304	4543	1390	4	2	0	2
Extremadura	1 075 286	1075	497	1	0	1	0
Galicia	2 750 985	2751	1037	5	4	1	0
Madrid	5 804 829	5805	1247	6	5	1	0
Murcia	1 294 694	1295	485	5	0	3	2
Navarra	584 734	585	222	1	0	1	0
Basque Country	2 115 279	2115	548	9	2	4	3
Rioja	293 553	293	82	0	0	0	0
Ceuta	74 654	75	23	0	0	0	0
Melilla	68 016	68	15	0	0	0	0
Total	43 197 684	43 195	13 999	111	30	43	38

^aEstimates of the Prelocutive profoundly Deaf population are based on the parameters used in an earlier study of mental health and deafness in Spain (Clowes, 2000).

^bTotal number of centres includes both mainstream and specific special educational schools which provide primary education in Spain (information on how many of them actually serve the needs of d/Deaf children is not available) (Office of Statistics, Ministry of Education and Culture—academic year 2003/04).

^cSchools with: at least one Deaf educator taking part in the bilingual experience, bilingual experience of more than 1 year, and collaboration of the school with a Deaf association.

reflection and action, the key informant survey method used in this study has several unique characteristics which we believe are the major strengths of this study. These relate to a Deaf community focus, Deaf community involvement and viewpoint and the use of a sample of key informant groups more extensive in its coverage than those used in previous research involving both providers and consumers of the service. Indeed while, as previously stated, it has been argued that most research in the field of 'special needs' populations is both exclusionary and alienating because of the way it treats these populations as passive non-participants (Stubbs, 1995; Leeson, 2001), many PAR researchers have pointed out that collaborative relationships with community members are difficult to establish, maintain and develop (Brydon-Miller,

1993; Krogh and Lindsey, 1999, Obinna *et al.*, 2005). In our study, the process of overcoming Deaf and hearing cross-cultural differences took a lot of discussion and was analogous to the ones described in research with Deaf community members (Jones and Pullen, 1992); however, the practical experience of engaging in the research process enhanced the group's ability to reconcile different agendas, build consensus and decision-making, engage in meaningful dialogue and develop a common strategy to attain goals. Partnership, participation and trust-building are viewed by the extended research team as the keystone of the project and as its main strength.

In interpreting the results presented here, the following methodological limitations should be borne in mind. First, in the absence of registers

of all those directly and indirectly engaged in the education of d/Deaf children, it is obviously very difficult to assess to what extent our key informant groups are representative of the target group, especially as intra-community differences and differences between urban and rural/isolated areas can be expected within each community, and the membership of some of these groups often overlaps. However, we believe that we have managed to survey an extensive geographical sampling, with information from both providers and consumers of the service including the perspectives of those who are less visible and are generally overlooked. Secondly, because questionnaire respondents were only asked to name schools in which, apart from the official language/s of their autonomous region, a sign language was used as a means of communication with d/Deaf and hard-of-hearing children, only schools using a bilingual approach were identified in our study. Since information on how many of the 13 999 schools providing primary education in Spain serve the needs of d/Deaf and hard-of-hearing children was not available at the time of the study, the extent to which those children are receiving adequate educational provision cannot be measured. Lastly, a third limitation, which is an inherent problem in d/Deaf education research, may have arisen from the terminology used in the questionnaire. Although the term 'bilingual education' for Deaf children has grown in popularity so that it is now a widespread model in many parts of the world, we purposively chose not to use this term in the questionnaire in our approach, in order to minimize biases derived from our inability to determine how respondents would interpret this term and/or whether they would confuse it with bilingual education used with hearing children in the bilingual Autonomous Regions. Instead, we used the more familiar terms 'spoken language/s' and 'sign language/s' even though we were aware that using the term 'sign language' could also somehow distort the responses to the questionnaire (Johnson, 1986, Woodward and Allen, 1987, 1988; Christensen, 1989; Hadadian *et al.*, 1997; Kyle and Allsop, 1998). The cross-section of key informants was intended to minimize this potential bias as well as one of the weaknesses associated with this technique; i.e., that the information derived from key informants often represents the perspectives (and biases) of the organizations,

agencies and associations with which these informants are associated (Marshall, 1996; VanLandingham *et al.*, 2005). Our impression is that, although on the basis of our findings, it seems likely that our results somehow over-estimate the extent of pilot bilingual experiences by confusion between the concepts of 'sign language' and 'sign supported Spanish', for the large majority of cases, informants were reasonably confident in the information they provided. Still, future research is clearly needed to enable investigation of these possibilities and corroborate the findings of this study.

Two interesting results of this study relate to the overall level of participation of different key informant groups and subgroups. Firstly and noticeably, except for the national and regional government administrations group, the parents' associations group showed a lower final response rate than all other key informant groups. This finding is particularly relevant for three main reasons: (i) special efforts were made to foster parental involvement through their national umbrella organization from the beginning of the project, (ii) some parents' organizations have a very active role and strong political influence in the Spanish context, especially as it relates to educational provision of d/Deaf children and (iii) parents' rights to be actively involved in the education of their children—especially long-excluded schoolchildren—has been widely recognized and promoted in many international policy statements and recommendations (UN, 1993; UNESCO, 1994; Knoors, 1996; UNESCO, 2000; Meijer, 2003). It should be noted though that this finding masks significant differences in parental participation (a 100% RR of newly 'pro-bilingual' parents' associations compared with 32.87% RR of the more traditional associations of parents of deaf children). Consequently, one possible explanation, which parallels those reported from some European studies on teachers and parents' initial attitudes towards the current EU inclusive education policy (Meijer, 1998, 2003; Meijer *et al.*, 2003), is that an older generation of parents' organizations may feel threatened by the current worldwide bilingual reform movement regarding their position and power as organizations and may therefore have felt that the questionnaire was irrelevant to them. Secondly, given that State and Autonomous School Councils, representing all the groups involved in education, are the national

and autonomous bodies responsible for advising the Government on legislation or regulations to be proposed and adopted, it is also surprising to observe the significantly low response from this group. The reasons for this finding may be related to the priority given by these participatory bodies to the Spanish Deaf community's educational needs and rights as an important policy concern; however, future research is needed to confirm this hypothesis which would question their role as appropriate advocating bodies for this vulnerable social group.

A few additional points need also to be highlighted. First, our finding that important regional differences exist in the occurrence of Deaf bilingual programmes within the country suggests that it is not possible to decide how best to close the equity gaps by focusing on those most in need without understanding not only inequalities between countries but also within societies. Secondly, it should also be borne in mind that although the findings of this investigation are somewhat encouraging in the sense that there has been a move towards progress in accordance with the UN Convention's standards, especially considering that d/Deaf education has been historically a very complex and debated issue in the Spanish context and that social and educational changes are always hard and slow to bring about, this study only identifies basic features of DBiBi programmes that are necessary but not sufficient preconditions for achieving the sort of substantial pedagogical and attitudinal changes in educational policy and practices which would lead to Deaf people being treated as equals. For this reason, our findings must ultimately be linked to a more in-depth analysis of key aspects of quality and effective Deaf bilingual education programmes and their relation with pupils' varied backgrounds (e.g. Deaf immigrants, ethnically and culturally diverse Deaf students, Deaf signers with language disorders), the larger school, family and community environments (Christensen, 1989; MacNeil, 1990; Rinne, 1996; Bergmann and Ravn, 2000; Fiedler, 2001; Bagga-Gupta, 2002; Evans, 2004; Morgan *et al.*, 2006).

In summary, Deaf communities as cultural minority groups and disability groups (as they are considered by the broader hearing community) currently face a unique set of barriers in accessing health-promotion programmes (Burgess *et al.*, n.d.; Kyle *et al.*, 1996; Sadler

et al., 2001; Ubido *et al.*, 2002; Jones *et al.*, 2005). We believe that our key informant survey provides valuable information that can be used as an entry point and a base upon which additional research in the under-explored area of health-promoting programmes for the Deaf communities in the school setting can be developed to improve the fit between needs and provision. Our findings suggest that developing approaches based on partnership and participation with Deaf communities can be effectively conducted, although further exploration is needed on the nature and extent of its true benefit for those communities. It is our hope that further research in this area will help build a theoretical framework for understanding the common principles underlying school health-promotion and Deaf bilingual education, will transform the theory into applicable, manageable and successful experiences and will guide health-planners and decision- and policy-makers on deciding how best to close the equity gaps and bring together educational policies under labels such as 'health-promoting schools', 'inclusive schools' and 'Deaf bilingual-bicultural schools'.

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