

Autism and Special Education Policy in Mexico

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In recent years, a great deal of scholarship has examined the adequacy of special education and other support services for children with disabilities in the U.S. and in other industrialized states. By contrast, there has been comparatively little study of services for children with disabilities in developing countries. In this paper, we attempt to bridge this gap in the literature. Focusing on the case of Mexico, we examine the provision of special education and other support services, and the availability and cost of private services. The focus of the analysis is on children with autism. Drawing upon a theoretical approach that combines modern political economy and comparative institutionalism, we also develop a tentative explanation of the politics of policy-making among parents and other stakeholders in the autism advocacy community.

INTRODUCTION

Since the early 1980s, governments in Latin America have implemented a wide range of social and health policy reforms. In the aftermath of the 1982 debt crisis, policy-makers in the region came under strong pressures from the International Monetary Fund and the World Bank to reduce social spending and to redesign social and health programs to be compatible with neoliberal economic reforms.¹ In addition to pressures emanating from international economic organizations, transnational policy networks and politically insulated “change teams” were also key to promoting social sector reforms.² Regardless of whether the origins of policy change were located at the systemic or domestic levels, by the mid-1990s it was plain to most observers that social policies had been radically altered throughout Latin America.

Social sector reforms in Latin America have had a profound influence on education policies in the region. A rich policy literature has documented effects of various reforms to regular education, ranging from decentralization plans, performance-based compensation for teachers, and vouchers.³ Yet, although the effects of reforms to *regular* education have been well studied, analysts have devoted comparatively little attention to recent changes in *special* education policy in Latin America.⁴ The lack of attention given to special education by analysts of comparative health and social policy is potentially significant. Human rights groups and policy-makers alike have come to recognize that people with disabilities in Latin America are subject to social exclusion and frequently end up living in poverty.⁵ In this context, the question of disability⁶ rights has become increasingly salient in selected countries in Latin America. There is also a strong presumption among regional health organizations that public policies for people with disabilities are not adequate. Indeed, in many cases, special education is the only major service provided by the state, and particularly for people with mental

and neurological differences. Viewed from this angle, the failure to adequately study changes in special education creates a large gap in our understanding of how Latin America's new democracies are addressing the needs of differently-abled people.

In this paper, we attempt to bridge this gap in the literature by focusing on the provision of public education policies in Mexico. Among the Latin American countries implementing changes in special education policy, Mexico's experience with reform has been particularly striking. After 1993, the government embraced a policy of inclusiveness and mainstreaming, to the maximum extent possible, for all children with disabilities. To date, however, only a small number of studies have examined the effects of Mexico's reforms.⁷ There has been virtually no research on the experience of specific groups of disabled students in Mexico covered by special education, including students with autism.⁸ A focus on children with autism can contribute to the comparative analysis of special education policies specifically and social sector reform in Latin America more generally. Given the high level of economic integration between the U.S. and Mexico, it is possible that the recent surge in media coverage of growth in autism in the U.S. has spilled over into the Mexican media market. If awareness of autism in Mexico is increasing, then it is possible that parents and advocates are scrutinizing the provision of special education policies, with attendant consequences for political organizing in the disability rights community.⁹

A focus on policy for children with autism can also contribute to a broader analysis of democratization in Latin America. Although there is some debate in the literature, recent scholarship has asserted that full democracies must provide a minimum of protections and opportunities for groups that are vulnerable to social exclusion.¹⁰ Because people with autism experience varying levels of behavior that is socially defined as "stereotyped," "impaired," or "socially challenged," they are at risk for experiencing poverty, social exclusion, and mistreatment via institutionalization.¹¹ The inability or unwillingness of policy-makers to provide adequate opportunities for people with autism and others with disabilities is suggestive of the barriers political regimes face as they attempt to transition from semi-democracies to full-democracies.

The analysis employs a case study¹² approach that utilizes different types of data. We draw partly on anonymous semi-structured interviews to analyze the effects of reform and the pattern of political activism among disability rights groups. Generated between 1999-2001 and 2006-2007,¹³ the interviews cover federal and state-level special education officials, psychologists and other professionals (e.g., speech therapists, behavioral intervention consultants), members of advocacy organizations, and other stakeholders in Mexico and the U.S. who work in Mexico's disability policy area. The information gleaned from interviews is augmented by contact with staff from U.S. autism clinics (who have worked in Mexico) and with analysis of quantitative data on services for children with autism provided by federal special education authorities.¹⁴ Although special education policies were reformed in the mid-1990s, we restricted the time frame for analysis to 1999 through 2006 in order to allow sufficient lag for the effects of reform policies to have an effect.

The paper is divided into four sections. In the first section, we examine the data on the prevalence of autism in industrialized countries and in Mexico. The second and third parts examine public special education and private programs for children with autism. Finally, in the fourth section, we examine the politics of policymaking, with a focus on the activities of disability rights and advocacy organizations.

AUTISM IN MEXICO: AN OVERVIEW

Data from recent studies suggest that prevalence of autism in industrialized countries may be higher than what had been estimated in previous research. In a review of 16 studies from 1993 to 2003 completed in the U.S., U.K. France, Sweden, Norway, Finland, and Japan, Eric Frombonne found that the median estimate of prevalence of autism and autism spectrum disorders from these studies was 1.3 per 1,000 children.¹⁵ In 2006, the Centers for Disease Control and Prevention (CDC) reported its first national estimate of ASD prevalence among children in the U.S. The CDC study, which did not distinguish among parent-reported diagnoses of childhood autism, ASD, or 'atypical' autism,¹⁶ suggested that the prevalence rate among children in the U.S. is between 5.5 and 5.7 per 1,000 children (or approximately one in 175, to one in 181 children).¹⁷ Studies of administrative prevalence in selected U.S. states (as measured by normalized prevalence of students receiving special education services) suggest a ten-fold increase from 1995 through 2004 in some areas.¹⁸ The reported increase in prevalence has been subject to debate; factors implicated in the trend include changes in diagnostic criteria, better surveillance, environmental exposure, genetic and environmental interaction, perinatal risk factors (e.g., pre-term delivery, etc.), parental age, and diagnostic substitution.¹⁹

In Mexico, epidemiological estimates of autism prevalence at the national or state level do not exist. Clinical studies and medical reports in Mexico tend to report prevalence rates that are based upon samples from the U.S. and U.K.²⁰ The only Mexican data available on autism prevalence refer to reports from surveys of families, as measured through a registry of minors with disabilities that was first completed in 1996.²¹ Morales²² notes that this survey, the *Registro de Niños con Discapacidad*, was national in its scope and yielded a total childhood disability rate consistent with estimated rates from other developing countries. According to the survey, the total number of children in Mexico identified with autism in 1996 was 45,956. We combined the registry data with Mexican census data for 1996 for the relevant age group in order to calculate (provisionally) a childhood autism rate (ages 0-15) in Mexico of approximately 1.43 per 1,000.²³ Because the registry data represent an undercount of the true prevalence of disability in the population, this estimate should be treated as provisional and with caution. Moreover, while members of advocacy organizations suggest that autism has increased in Mexico, we lack any longitudinal data on the growth trajectory of autism since the 1990s.

Social acceptance of people with disabilities, including people with autism, varies throughout Mexico.²⁴ Although the government has attempted to find employment for adults with disabilities, many face discrimination in the labor

market (where unemployment is already a problem) and other forms of social exclusion. Given the social stigma associated with disability, the incidence of autism among children within the family can magnify many other challenges Mexican families may encounter. The problems faced by families who care for children with autism in Mexico tend to be, to a large extent, similar to issues mentioned in studies from the U.S. and other industrialized countries.²⁵

Due to the persistence of folk beliefs²⁶ and misinformation about the sources of disability, families with children with autism report isolation or distance from other members of their extended family, changed behaviors among siblings, and feelings ranging from depression to burnout.²⁷ Economic resources are frequently cited cause of familial stress, as parents attempt to secure the necessary funds to find appropriate support services or treatment²⁸ for their child.²⁹ Mothers of children with autism in Mexico report being most affected by the child's disability, since they are seen to be the primary caregivers and are expected to provide extra care and support; in some cases, women are compelled to quit their jobs in order to provide additional care (exacerbating economic stress in the family unit). Fathers may spend less time at home after the diagnosis or abandon the family, leaving the mother to assume most of the responsibilities associated with the child with autism and his or her siblings.³⁰ The expectation that women should assume the primary care-giving role for a child with disability would appear to be associated with the manner in which gender roles are constructed in the Mexican household; it also reflects gendered attitudes toward disability which emphasize that mental disabilities among children are the fault of the something the mother has done.³¹

SPECIAL EDUCATION SERVICES FOR CHILDREN WITH AUTISM AND OTHER DISABILITIES

Having discussed the estimated prevalence of autism in Mexico and the situation facing families with autistic children, we turn now to an analysis of special education services, the mainstay of the state's service delivery model for children with disabilities.

The decade of the 1990s saw important changes in Mexico's educational system. After securing the consent of the leadership of some opposition parties and the national teachers' union (*Sindicato Nacional de Trabajadores de Educación*, SNTE), the Salinas administration (1988-94) engineered a major reform of the education system in 1992. Under the new policy, which involved a significant degree of devolution, educational administrators at the state level were given more flexibility to meet the constitutional requirement of providing children with a basic education through the eighth grade. Subsequent reforms modified policies with regard to the provision of special education services. Pursuant to 1993 amendments to the Mexican Constitution (Article 3), the Mexican Congress approved a new education law that specifically recognized that children with disabilities have the right to receive public education through the eighth grade.³²

In principle, the new federal special education policies adopted in 1993 were extremely progressive. To the maximum extent possible, school

administrators and teachers were required to educate children with disabilities in the regular classroom environment. The law established a goal of inclusion but also provided for the possibility of partial or total placement in specialized settings for children with severe disabilities. New mandates also required state governments to train regular classroom teachers in the new model for special education and to provide greater resources to families with disabled children.

The process of identifying a child with disabilities, including children with autism, changed with the new policies. Under new criteria implemented after 1995, a child who demonstrates difficulty in acquiring the curriculum for her grade may be identified as at risk and deemed eligible for special education services.³³ The reference point for performance is the student's peer group.³⁴ Subsequently, in the process of reevaluating curricular goals and teaching methods for a student identified as at risk, a multidisciplinary team may analyze the nature of the student's disability (if any) and her present levels of performance based upon "curricular assessments," observation, and interviews with teaching staff and caregivers.³⁵ In a small government study of children with autism receiving special education in Mexico City, children classified as "autistic" exhibited many symptoms that were consistent with the Diagnostic and Statistic Manual (DSM) IV criteria for autism spectrum disorder.³⁶ It is worth emphasizing, however, that staff persons who conduct initial diagnoses are not required (and frequently do not employ) diagnostic test instruments³⁷ to determine whether a child falls on the autism spectrum or to certify eligibility for special education services.³⁸

Since the mid 1990s, children with disabilities including autism have been offered public special education services primarily through two programs, Units of Support Services for Regular Education (*Unidades de Servicios de Apoyo a la Educación Regular*, USAER) and Centers of Multiple Attention (*Centros de Atención Múltiple*, CAM). Both programs were the product of educational reforms discussed previously (see Table 1).

Table 1: Changes in Early Intervention and Special Education Services, Mexico, 1985-2005

Year	Special Education Schools	Centers for Multiple Attention	Centers for Training	Psycho-pedagogical Centers	Units of Integrated Groups	Centers for Early Intervention	Diagnostic Centers	Units of Support Services for Regular Education
1985	476	---	67	279	543	13	---	---
1990	656	---	86	485	576	35	40	---
1995	824	---	90	580	334	55	30	376
1996	919	---	73	343	264	41	9	815
1997	169	910	71	136	136	28	10	1382
1998	135	1031	57	69	54	19	17	1648
1999	103	1144	40	40	37	11	---	1922
2000	100	1197	37	27	17	8	---	2180
2001	85	1253	36	27	16	7	---	2298
2002	81	1278	33	18	16	6	---	2527
2003	70	1296	32	15	16	4	---	2768
2004	70	1321	31	14	16	4	---	2751
2005 ^a	72	1352	32	14	16	4	---	

Note: A dash (--) indicates no data because observation is prior to creation of new program in 1995, or because observation is after program was eliminated by reforms in 1995.

^a Preliminary figures for the year.

Source: Instituto Nacional de Estadística, Geografía e Informática (INEGI), *Anuario Estadística de los Estados Unidos Mexicanos* ed. 2005 (Aguascalientes, México: INEGI), 2005, Table 4.37.

USAERs serve children whose disabilities are not so severe as to prevent placement in a regular classroom environment. Although there is some variation in the administrative structure of USAERs across different states,³⁹ in general, each unit tends to be composed of a multidisciplinary team that includes several special education teachers, a social worker, a psychologist, and a speech therapist.⁴⁰ Each USAER team is responsible for completing an initial evaluation of a student, for implementing changes in curricular goals and instructional methods with teachers, and for working in individualized sessions with students (inside the classroom, or in more contained environment at the school). USAERs also provide training for parents and coordinate supplemental health services as needed for children.⁴¹ Under current guidelines, each USAER is designed to provide up to 30 on-site visits annually to five schools with an average caseload of 20 students.⁴² During the 2005-2006 school year, government data indicate that USAERs provided special education services to 328 children with autism in Mexico (Table 2).

Table 2: Number of Children with Autism Served in USAER and CAMs, 2005-06 School Year

USAER	CAM	CAPEP	Total
328	914	353	1,595

Source: Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial* (Mexico, D.F.: SEP, 2006), 25.

By contrast, “basic” CAMs⁴³ are designed to provide special education to children with severe forms of autism or other disabling conditions that create barriers to learning in a regular classroom environment. Typically, a student is placed in a CAM only after a USAER team has recommended such a placement and the parents have given their consent.⁴⁴ As in regular schools served by USAERs, basic CAMs make appropriate modifications with the goal of helping students with disabilities acquire the core curriculum. Students with differing disabilities are grouped together based upon their present levels of performance; class size in each CAM varies but may range from 10 to 20 students.⁴⁵ Students in CAMs may also receive supplemental support services from other programs, including speech therapy, behavior management, etc.⁴⁶ The Ministry of Education reported that CAMs served a total of 914 children with autism throughout Mexico in the 2005-2006 school year (Table 2).⁴⁷

As in other countries, the special education programs established to serve children with autism in Mexico face a number of challenges in the area of coverage and performance. First, due to the strong commitment to “neoliberal” economic policies across the last three presidential administrations in Mexico, government spending for special education has not been adequate.⁴⁸ As a result, there is a serious coverage gap between the potential demand for special education services and its provision. A rough estimate of the coverage gap for children with autism, which we calculated with the 1996 registry data of children

with autism and more recent data on children with autism enrolled in special education programs (USAER, CAM, and other programs,) suggests that only 3.5 percent of Mexican children with autism were receiving special education services in 2005.⁴⁹ Studies of families who have children with autism echo these findings. For example, Araujo Campbell and Figuera Duarte found that families in search of the appropriate services for their child with autism had a very difficult time finding qualified medical, psychological and educational personnel. With respect to special education services in particular, parents mentioned the absence of adequate facilities and revealed that their children were frequently transferred from one special education institute to another. In some cases, the school failed to identify the disability or even withheld the diagnosis of autism from the parents so they wouldn't reject the child.⁵⁰

The coverage gap for children with autism is also reflected in spatial terms and mediated by ethnicity and poverty. According to government data, USAERs, CAMs and other special education support services were available in only 42 percent of municipalities, with a clear bias toward wealthier cities with larger population in Mexico;⁵¹ more recent data from 2006 showed virtually no change in this figure.⁵² Children with autism and other disabilities who are indigenous or who live in poor, rural areas are therefore at significant risk of not having access to any public special education services.⁵³ In light of this, it was not surprising that a psychologist in a rural area of Tampico noted that publicly provided resources for special education create and sustain "little infrastructure, administrative and physical"⁵⁴ for special education.

The lack of sufficient resources has also led to staff shortages and inadequate training, with the effects of diminishing the efficacy of special education for all students with disabilities, including those with autism. In its national evaluation of USAERs completed in 2002, the Ministry of Education noted that USAER teams tend to serve more schools and students than provided for in the program's design (20 students, five schools). Instead of conducting 30 on-site visits to five schools during the year, as contemplated in the policy, many USAER teams serve more than five schools and are able to provide only 10 visits or less annually, with attendant consequences for the quality and intensity of services.⁵⁵ Fletcher et al.'s (2003) study of USAERs in Mexico City and Guanajuato -- which covered some schools that enroll students with autism -- reached similar conclusions. They found that due to staffing shortages, some schools received no services from USAERs; in other cases, even when USAER teams were able to provide services, there was a lack of coordination with regular teachers and inadequate training of regular teaching staff on the new model.⁵⁶ Respondents covered by our study also emphasized the lack of adequate training. For example, a school staff member in Coahuila explained "there are national congresses [for training] in Mexico City, but we haven't been able to send teachers because we don't have a lot of money."⁵⁷ Likewise, a national survey of USAER teams completed in 2006 by the *Red Internacional de Investigadores y Participantes sobre Integración Educativa* found that 72 percent of team members felt that the Ministry of Education was not providing sufficient training and services to facilitate inclusiveness, while 65 percent stated that

students lack sufficient school supplies, and 73 percent stated that infrastructure guaranteeing physical access is insufficient.⁵⁸

Resource constraints and staff shortages have also hampered CAMS, the other mainstay of special education in the new model of service delivery. The Fox administration was forced to admit in 2006 that the situation had changed little since 2002: There is a serious teacher shortage for CAMs and little growth in the number of teachers' colleges offering training for people who wish to enter special education teaching CAMs.⁵⁹ In addition, the fragmentary evidence suggests that the staff-to-student ratios in some CAMs are higher than what has been suggested in the rigorous, peer-reviewed literature on efficacy for educating children with autism.⁶⁰

Finally, there is little systematic information regarding the efficacy of teaching methods and strategies used by USAERs and CAMs for children with autism. A small number of research units at several universities in the U.S. and elsewhere have developed comprehensive programs that have been shown (in highly selective, peer-reviewed publications) to help children with autism make gains in the domains of speech, social interaction, and cognitive skills.⁶¹ Nevertheless, based upon contacts of staff in these centers, we found that none had provided professional training to educational staff at the federal level or in local public schools in Mexico in recent years.⁶² Furthermore, it remains unclear how much the published work of these research units has become integrated into special education services for children with autism. In Mexico City, for example, the most recent training program for children with autism and adolescents conducted by the *Dirección de Educación Especial* employed a neo-Freudian, psychoanalytic model derived from the French psychologist Lacan.⁶³ Significantly, the approach rejects direct, one-on-one instruction with students with autism (while retaining, at least, an emphasis on a structured environment); the Lacanian method is not been among the group of methods shown to have efficacy in the peer-reviewed scientific literature.⁶⁴

PRIVATE SERVICES

A number of private schools, clinics, and associations in Mexico also offer children with autism special education and a range of other treatments and services, ranging from interventions grounded in applied behavioral analysis, to those that focus on speech, nutrition, or Lacanian⁶⁵ therapy. Relatively state-of-the-art, some schools are created and operated by parents. As one professional consultant noted:

Most parents in Mexico form non-profit associations. Some associations build and run schools for their own children. I train parents and teachers of schools controlled by parents. I want the technology to go to those that can use it every second of the child's waking life. I normally do not teach psychologists or therapists. In Mexico it is still a very clinical model and the therapies provide behind-the-door therapy that the parents never see.⁶⁶

As the data in Table 3 suggest, organizations providing private services tend to be concentrated in states that have a higher degree of wealth, as measured

by real gross state product (GSP) per capita. As in the case of public special education, then, private services are biased toward wealthier areas of Mexico. Indeed, real GSP per capita has a statistically significant effect ($p < .001$) on the level of private clinics in each state.⁶⁷

Table 3: Number of Clinics and Associations Offering Special Education, Intervention Service and Training for Children with Autism, by State (2006)

<i>State</i>	<i>Cities with Private Services</i>	<i># Clinics and Associations per State</i>
Aguascalientes	Aguascalientes	1
Baja California	Tijuana	1
Chihuahua	Juarez (2) Chihuahua	3
Federal District	Mexico City (16)	16
Jalisco	Guadalajara (2)	2
Morelos	Puebla	1
Nuevo León	Garza Garcia Montérrey	2
Sinaloa	Culiacan (2) Mazatlan	3
Sonora	Hermosillo	1
State of Mexico	Tultepec Meteppec Cuautitlán Izcalli Toluca Naucalpan Polanco	6
Tamulipas	Victoria Tampico	2
Yucatan	Merida (2)	2
Total		40

Source: Unpublished lists compiled by Dirección de Educación Especial, Mexico City.

Systematic data on the cost of private services are not available, but the costs of psychological services for children with disabilities of US\$ 8 to 10 per hour reported in Baker⁶⁸ and other sources is far above the earnings of those receiving minimum wages and twice as much as average hourly wages in 2004 received by unionized automobile workers, among the highest paid workers in Mexico's industrial sector.⁶⁹ If we assume conservatively that private psychological services were offered to children for two hours per week, this would come to approximately 13 percent of the average monthly gross pay received by unionized automobile workers.⁷⁰ Factoring in the start up costs of home and private service, including initial evaluation and an average of 24 hours of staff

training provided by consultants, the costs for private home services are probably much higher. In light of this, it is hardly surprising that Araujo Campbell and Figuera Duarte⁷¹ found that some parents of children with autism report selling their assets (e.g., automobiles, real estate, furniture) to pay for private services. Some child psychiatrists report providing services for free to children with autism, but this would appear to be a limited practice.⁷² Government funding to cover tuition is available for only one clinic located in Mexico City.

The efficacy of treatments offered by private service providers may also vary. Employing methods shown to have efficacy, the Lovaas Institute, a U.S.-based research institute, has provided training to staff in a private program in Mexico. Some other Mexican programs offer private school and home-based programs using methods that have been shown in rigorous peer reviewed studies to have efficacy in producing gains in speech, social interaction, and cognitive skills. This includes most of the intensive methods using applied behavior analysis.⁷³ Nevertheless, it remains unclear that the methods for behavioral interventions developed in clinical studies are being implemented in private programs in Mexico. In addition, there are a number of other methods used in private programs – including many nutrition therapies – that generally have not been shown to have efficacy in the peer-reviewed, scientific literature.⁷⁴

THE POLITICS OF POLICY FOR CHILDREN WITH AUTISM IN MEXICO: A TENTATIVE EXPLANATION

To summarize the findings thus far, education policy for children with autism in Mexico remains extremely fragmented and is of variable quality. Public special education policy is characterized by inadequate coverage, low levels of resources, and programming that is of questionable efficacy. Nearly all private-based services are restricted to a small number of states and are beyond the reach of many poor and lower-middle-class families.

Although new advocacy groups have tried to raise awareness about autism spectrum disorder in Mexico, there is little evidence that parents and other stakeholders are mobilized politically to bring pressure for change in public policy, either at the federal or state level.⁷⁵ Instead, the political activities of advocacy groups tend to be sporadic and limited to certain geographic areas, such as the Federal District of Mexico City. The policy framework for children with autism and other disabilities continues to be formulated at high levels, with little input from parents or groups representing individuals with disabilities.

In explaining the relatively low levels of political action and the centralized pattern of policy formulation, we draw on theoretical approaches that focus on the political economy of group mobilization, the coherence of movements representing individuals with disabilities, the dynamics of Mexico's party system, and the structure of the Mexican state. To be sure, much of the recent literature associated with the minority group model of disability, which is grounded in constructivism, has been extremely useful in clarifying the process through which a "disability identity" is socially constructed for people with disabilities and their families.⁷⁶ Nevertheless the social process through which individuals experience difference, social exclusion, and inadequate service provision is only a necessary,

but not sufficient condition for political action. To understand the fragmented trajectory of political organizing among Mexicans in the autism community, one must move beyond constructivism. In what follows, we expand the analysis to examine the political economy of group organization, the cohesiveness and ties among autism advocacy groups and other stakeholders, and the structure of the Mexican state.

Group Formation

We begin with an exploration of the political economy of group mobilization. The starting point is to see whether there are strong incentives for one to demand improvement in the provision of public services for children with autism.⁷⁷ As in other countries, the degree to which parents⁷⁸ or caregivers of children with autism living in Mexico have an interest in shaping *public* policy varies and is mediated by social class and income. As noted, some parents may abandon the family following diagnosis or to seek to hide their child's disability from public view. As a psychologist working with very young children noted, "...in the lower and middle classes, parents used to hide their kids and not give them any education...the family would say that the child had a problem and that was all."⁷⁹ Parents or family members who engage in exit strategies or concealment are unlikely to be interested in demanding changes in public policy.⁸⁰ At the same time, families with higher levels of wealth who remain committed to providing treatment for their children frequently choose *private* service. Several of private schools are relatively state-of-the-art and, as result, as a therapist from Mexico city put it when discussing options for children with autism in Mexico, "if I have someone with money, I send them there [to private schools]."⁸¹ Inasmuch as the children of wealthy parents are not part of the potential pool of clients covered by public special education programs, wealthier parents who "opt out" of public goods have a weaker incentive to demand changes in public policy, all things being equal. The potential base for political mobilization, then, tends to be concentrated among working and lower-middle-class parents with children that are covered (or potentially covered) by public programs, and who are willing to be open about disability. These parents are also willing to be public about disability.

Table 4: Autism Advocacy Groups Registered with the Government, Mexico, 2002

State	# of Associations	Group Membership
Aguascalientes	1	300
Baja California	1	n.d.
Yucatán	1	26
Estado de México	3	369

SOURCE: INEGI, *Directorio nacional de asociaciones de y para personas de discapacidad* (Aguascalientes, Mexico: INEGI, 2002).

Among parents who have an interest in improving policies for children with autism, political participation may still prove to be costly. Given the large

problems that plague Mexico's public education system, potential group members may feel extremely uncertain about whether campaigns to improve special education services will be successful. In this context, parents might carefully weigh the opportunity costs associated with their expenditures of time and resources on group action. Instead of engaging in collective political action, some parents of modest means may choose alternatives, including the formation of small non-profit associations that pool resources to provide private services. The fragmentary evidence suggests that some parents choose such a strategy.⁸² In this way, the potential base of membership in advocacy groups is further diminished.

Lack of Cohesiveness among Disability Groups, Problems in Linkages to other Stakeholders

Parents who have an interest in changing public policy and who choose to become involved politically face additional barriers at the stage of group formation. Part of the challenge, according to a director of communication at an institute that works with children with disabilities including autism, is that "people don't understand the fundamental ideals" of modern special education policy.⁸³ It is relatively easy to reach agreement about the importance of advocating for additional resources for schools and other support services, but there are divisions around the issue of efficacy of different treatment programs, with some parents interested in nutritional therapies, and others interested in methods ranging from behavioral interventions to art and music therapy. These divisions are, in fact, evident in the number of small associations supporting different types of treatment therapies (see Table 3). Larger associations, including the Mexico branch of the *Federación Latinoamericana de Autismo* (FELAC), and the *Sociedad Mexicana de Autismo* (SAM), seek to lobby for change and to coordinate activities among the smaller groups. Yet, as in the U.S., both FELAC and SAM have avoided endorsing specific treatments, which has limited the scope of demands they can make with the government.⁸⁴

Although the prevalence of autism in Mexico is now estimated to be higher than other types of neurological disability (e.g., Down's Syndrome, childhood epilepsy, etc.), its prevalence is far lower than prevalence for many other physical disabilities. The density of members from autism advocacy groups in any legislative district or state in Mexico is therefore likely to be very low. Given the increasingly competitive nature of Mexico's electoral system, parties and candidates are unlikely to become interested in the issues raised by autism advocacy groups unless they are linked to the broader agenda of larger disability groups or larger groups representing other interests. In recent years, however, it is not clear that the main autism advocacy organizations have developed strong links to other larger organizations representing people with disabilities in Mexico. Although some contact has been made at national meetings, there is little evidence of sustained contact or development of a common policy agenda. Moreover, there are potential barriers to cross-group cooperation. The therapies and programs that benefit children with autism and other developmental disabilities are fairly specific and might not be of much interest to groups

representing those with physical disabilities.⁸⁵ The challenge of developing stronger group ties is to find common points of agreement in a policy platform. The scarcity of economic resources raises the potential that disability groups choose instead to compete for resources and divide along the lines specific to type of disability.

The potential influence of advocacy groups representing the disabled has also been weakened somewhat by the absence of ties to key stakeholders, including the national teacher's union (SNTE). If disability advocacy groups were to forge ties to the SNTE around a common agenda, it would likely draw the attention of major political parties. Such an outcome has proved elusive, in part, because the SNTE is itself divided over the policy of inclusiveness in special education.⁸⁶ Indeed, although the SNTE and government special education officials have tried to find common ground over the policy, some regular school teachers oppose the policy of inclusion or feel that it has worked poorly, possibly increasing their effort levels in the classroom. A special education teacher from Puebla noted that the best attribute of the new special education policy is "...the policy of integration. Students now go to school with everybody. However, there is a strong union of teachers who don't feel that integration is such a good idea."⁸⁷ Fletcher⁸⁸ found similar resistance among unionized members of the regular teaching staff in schools in Mexico City and Guanajuato. Compromise over the policy would seem to be tied over issues of control over the "labor process" – i.e., in clarification of the role and authority of regular school teachers versus USAER teams in the regular school classroom – and other issues related to teacher's salaries and effort levels. Until the SNTE becomes more cohesive in its support for inclusion, autism advocacy organizations and the union will not be able to build cohesive support for change – and this tends to diminish their political value when political parties are setting the political agenda.

The Structure of the Mexican State

Finally, although Mexico's electoral system is becoming more competitive, the legacy of "state-corporatism" in Mexico continues to have an influence over policy formulation.⁸⁹ The ministries that make social and education policy for people with disabilities have long enjoyed a high degree of autonomy from societal interests. There is a long tradition of including in policy formulation only those interest groups that were organized by the regime⁹⁰ or who have official recognition. Thus, when the special education reforms were adopted in the 1990s, the SNTE was included in negotiations because the union had ties to the former ruling Institutional Revolutionary Party (*Partido Revolucionario Institucional*, PRI).⁹¹ Disability advocacy organizations were largely excluded from the process of formulation for special education. Although Vicente Fox is a member of the National Action Party (*Partido Acción Nacional*), during his administration (2000-2006) he continued the tradition of relying upon state corporatism in special education policy formulation. This has meant, among other things, that disability advocacy organizations have limited channels to influence policy formulation in the area of special education for children with autism.

CONCLUSION

This paper has examined the recent provision of public and private programs for children with autism living in Mexico. The findings suggest that public special education programs have limited coverage, suffer from a lack of resources, and employ teaching methods that may be of questionable efficacy. Although resource constraints are more severe in Mexico than in other industrialized states, Mexico's experience with special education reforms bears a crucial similarity to the trajectory of special education in the U.S.⁹² In addition, private programs in Mexico are varied in terms of the likely quality of programming and remain concentrated in wealthier states and are too costly for many families. The anecdotal evidence suggests that parents of children with autism are frustrated with the inadequacy of public services, but there is little evidence that this frustration has been translated into sustained political activism or lobbying through advocacy organizations. This outcome, we have suggested, is a result of the barriers to group formation, a lack of cohesiveness among disability rights organizations and other stakeholders, and the structure of the Mexican state.

The findings of this study have several broader implications for the comparative study of health and education policy for people with disabilities. Our analysis of the Mexican case points to the importance of national context, and especially prior institutional arrangements among key actors (e.g., "corporatist" labor unions and the state) and resource constraints as having a large influence on the performance of special education programs in the post-reform period. Likewise, even though several Latin American states have converged in formulating an inclusive special education policy, it is far from clear that the outcomes of these reforms have been similar.⁹³ Future comparative research might consider whether the presence or absence of institutional factors and other variables has influenced the success (or failure) of such reforms in Latin America and in other developing areas.

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¹ Chris Abel and Colin Lewis, "Exclusion and Engagement," in Abel and Lewis (eds), *Exclusion and Engagement: Social Policy in Latin America* (London: Institute for Latin American Studies, Cambridge, 2002), 3-53.

² Merilee Grindle, "Despite the Odds: The Political Economy of Social Sector Reform in Latin America," in Abel and Lewis (eds), *Exclusion and Engagement: Social Policy in Latin America* (London: Institute for Latin American Studies, Cambridge, 2002), 83-110; John P. Tuman, Sheniz Moonie and Danielle Roth-Johnson, "The Administrative Prevalence of Autism Spectrum Disorders in Nevada School Districts: A Pooled Time Series Analysis, 1995 to 2004," Working Paper, Center for Autism Spectrum Disorders, University of Nevada, Las Vegas, 2007, http://www.unlv.edu/cgiwrap/docsped/center_autism/index.php?page_id=22 (accessed November 20, 2007).

³ See, e.g., Marcial Boo, "Ideology and Education: Equity and Efficiency," in Abel and Lewis (eds), *Exclusion and Engagement: Social Policy in Latin America* (London: Institute for Latin American Studies, Cambridge, 2002), 245-265; Andrew Nickson, "Education Reform in Latin America: Decentralization or Restructuring," in Abel and Lewis (eds), *Exclusion and Engagement: Social Policy in Latin America* (London: Institute for Latin American Studies, Cambridge, 2002), 266-284; Carlos Ornelas, "The Politics of Privatisation, Decentralisation and Education Reform in Mexico," *International Review of Education* 50, Nos. 3-4 (2004): 397-418; Ernesto Schiefelbein and Paulina Schiefelbein, "Paradoxes of the Chilean Education Reform, 1989-2000," in Abel and Lewis (eds), *Exclusion and Engagement: Social Policy in Latin America* (London: Institute for Latin American Studies, Cambridge, 2002).

⁴ Exceptions include: Todd Fletcher, Carlos Dejud, Cynthia Klinger and Isabel Lopez Mariscal, "The Changing Paradigm of Special Education in Mexico: Voices from the Field," *Bilingual Research Journal* 27, No. 3 (2003): 409-430, and Dana Lee Baker "Children's Disability Policy in a Global World: A Question of Convergence," in Levi-Faur and Vigoda-Gadot (eds) *International Public Policy and Management* (New York: Marcel Decker, 2004), 221-48). Most of the research reported in Artiles, Trent and Hallahan did not take into account the recent reforms (post-1993) to special education. See Alfredo J. Artiles, Stanley C. Trent, and Daniel P. Hallahan, "Special Education for Students with Mild Disabilities in Latin America: Issues and Prospects," in Alfredo

Artiles and Daniel Hallahan (eds), *Special Education in Latin America: Experiences and Issues* (Westport, CT: Praeger, 1995), 251-284.

⁵ Pamela Dudzik, Ann Elwan, and Robert Metts, *Disability Policies, Statistics, and Strategies in Latin America and the Caribbean: A Review* (New York: Inter-American Development Bank, 2000), Available at <http://www.iadb.org/sds/Rev2bEditedDisability-PolicyDudzikElwanMetts.pdf> (accessed November 1, 2007).

⁶ In using the term “disability,” we follow the convention employed in the research literature. A more inclusive approach might refer to people with mental or developmental disabilities as being neurologically different or differently-abled.

⁷ See, e.g., Sofialetica Morales, “Bridge over Troubled Water: Collaboration between the United States and Mexico on Behalf of Individuals with Disabilities,” *Bilingual Review* 24, No. 1/2 (Jan.-Aug. 1999): 109-120; Baker, “Children’s Disability Policy in a Global World,” and Fletcher et al. “The Changing Paradigm of Special Education in Mexico.”

⁸ In the clinical psychological literature, “autism” is used to refer to a spectrum of “disorders” characterized by delays in language, a lack of social interaction, stereotyped behavior, restricted interests, and rigidity (insistence on sameness). Autism is evident by 24 months of age. In much of the literature, researchers use “classic autism” to describe cases where the clinical manifestations of the disorder are severe. The terms “autism spectrum disorder” (ASD) and “pervasive development disorder” (PDD) are used to describe children who show commonality in behaviors associated with autism but where the severity of the disorder in any one domain (e.g., speech, social interaction, etc.) may be less or absent. In discussing these criteria, we in no way seek to deny the importance of how disability is socially constructed, a process that frequently obscures how “typical” and “normal” development and behavior are defined and measured in society and by institutions.

⁹ In Mexico, see the program Noticieros Televisa, “Autismo: Profundos silencios” September 7, 2004 www.esmas.com/noticierostelevisa/losreporteros/390206.htm (accessed April 20, 2006). Other popular magazines and major news organizations in the U.S. have carried a number of stories as well. See, among others, NBC, “Autism: The Hidden Epidemic”, available at <http://msnbc.msn.com/id/6976337/> (accessed October 4, 2006); CNN, “Inside Autism,” available at <http://cnn.com/2006/HEALTH/07/28/autism.overview/index.html> (accessed September 4, 2006); *Time Magazine*, “Inside the Autistic Mind (Cover Story),” available at <http://www.time.com/time/magazine/article/0,9171,1191843,00.html> (accessed October 4, 2006);

Time Magazine, “The Secretes of Autism,” available at <http://www.time.com/time/magazine/article/0,9171,1002364,00.html> (accessed October 4, 2006);

Newsweek, “Girls, Boys and Autism (Cover Story),” Vol. 142, No. 10 (2003): 42-50; *Newsweek*, “When Does Autism Start? (Cover Story),” Vol. 145, No. 9 (2003): 44-53; *Newsweek*, “Talking Points,” Vol. 147, No. 19 (2003): 13.

¹⁰ Peter Smith *Democracy in Latin America* (Oxford: Oxford University Press, 2005).

¹¹ As Santana and Santana note, in Mexico, there is more acceptance of people with physical disabilities as opposed to people with mental and developmental disabilities. Although there has been some change, many people with developmental disabilities experience social exclusion and end up in institutions. See Sandra Santana and Felipe Santana, *An Introduction to Mexican Culture for Rehabilitation Service Providers* (Buffalo: Center for International Rehabilitation Research Information and Exchange, State University of New York, 2001). A report by Mental Disability Rights International on conditions in Mexican psychiatric institutions that house adults and children with developmental and mental disabilities reported lack of hygiene, lack of human contact and inappropriate use of restraints, among other things. See Mental Disability Rights International, *Human Rights and Mental Health* (Mexico and Washington D.C.: MDRI, 2000). In Paraguay, an investigation by Mental Disability Rights International led to the liberation of two brothers with autism who were, according to Allison Hillman, “...locked naked in tiny isolation cells without access to bathrooms. They lived among their own feces and urine in cells that were almost completely bare...Each boy was infested with lice, covered with scars, and spent approximately four hours every other day in an outdoor pen, which was littered with human

excrement, garbage, and broken glass.” See Allison Hillman, “Human Rights and Deinstitutionalization: A Success Story in the Americas,” *Pan American Journal of Public Health* 18, No. 4/5 (2005), p. 375. Regarding the connection between poverty and people who have developmental disabilities, see Dudzik, Elwan and Metts, *Disability Policies, Statistics, and Strategies in Latin America and the Caribbean*.

¹² Although the analysis focuses on only one case, the argument is potentially instructive for an understanding of other cases in Latin America. In future work, we plan to investigate cases in Chile and Brazil in order to examine the robustness of the argument. Given the lack of research in this area, beginning with a single case is useful.

¹³ The Mexican sample (from Baker’s research) included 50 stakeholders, followed up (in 2006) with contact with interviews of five Mexican officials who work in Federal special education, and contact (e-mail) with six staff members from U.S. research clinics and organizations that have either provided training and consultations in Mexico or who have had a history of providing training and consultations in Latin America. For more extensive information on the core interview questions and research strategy, see Baker, “Children’s Disability Policy in a Global World.” Because many respondents in the network of service providers may not be easy to reach, and because we were not interested in statistical generalization, we employed purposive some sampling techniques. We used government information (web sites, directories) to contact all government elites in the area of special education for children with autism in follow-up interviews in 2006. We also used snowball techniques, which involve referrals, to identify other stakeholders such as psychologists, behavioral therapists, advocates, family members, etc.; see H. Bernard, *Social Research Methods* (Thousand Oaks: Sage, 2002).

¹⁴ See, e.g., Secretaria de Educación Pública, *Programa Nacional para el fortalecimiento de la educación especial y de la integración educativa* (Mexico, D.F.: SEP, 2003), and Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial* (Mexico, D.F.: SEP, 2006).

¹⁵ Eric Fombonne, “The Epidemiology of Pervasive Development Disorders.” In *The Neurobiology of Autism*, ed. Margaret L. Bauman and Thomas L. Kemper (Baltimore: The Johns Hopkins University Press, 2005), 5, and Table 1.1. See also Christopher Gillberg, “The Epidemiology of Autism,” in Mary Coleman (ed), *The Neurology of Autism* (Oxford: Oxford University Press, 2005), 119-136.

¹⁶ Center for Disease Control and Prevention, “Mental Health in the United States: Parental Report of Diagnosed Autism in Children Aged 4-17 Years, United States, 2003-2004,” *MMWR Weekly* 55, No. 17 (May 5, 2006): 481-486. Because the Centers for Disease Control and Prevention (CDC) did not ask parents to distinguish among parent-reported diagnoses of autism, atypical autism, and other ASD disorders, it is not clear that the new U.S. prevalence estimates can be compared to ones of previous studies. CDC noted that children with the less severe forms of autism, e.g., Asperger and pervasive developmental disorder—not otherwise specified, were probably reported as having autism in this survey.

¹⁷ Centers for Disease Control and Prevention, “Mental Health in the United States: Parental Report of Diagnosed Autism in Children Aged 4-17 Years, United States, 2003-2004.”

¹⁸ Tuman, Moonie and Roth-Johnson, “The Administrative Prevalence of Autism Spectrum Disorders in Nevada School Districts.”

¹⁹For a discussion of various factors, see Gillberg, “The Epidemiology of Autism”; Heidi Larrson, William Eaton, K. Madsen, M. Vestergarrd, Anne Olesen, Eseben Agerbo, D. Schendel, P. Thorsen, and P.B. Mortensen, “Risk Factors for Autism: Perinatal Factors, Parental Psychiatric History, and Socioeconomic Status,” *American Journal of Epidemiology* 161, No. 10 (2005): 916-925. Debate concerning the effects of diagnostic substitution – i.e., the hypothesis that children previously classified as having “mental retardation” or “learning disability” have been reclassified now as “autistic” – is advanced in Paul T. Shattuck, “The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education,” *Pediatrics* 117 (2006): 1028-1037. For a critique, see John P. Tuman, Danielle Roth-Johnson, and Jennifer Vecchio, “Diagnostic Substitution and ASD: A Brief Comment on Shattuck.” *Pediatrics* May 19, 2006 (on-line letters). <http://pediatrics.aappublications.org/cgi/eletters/117/4/1028> (accessed May 19, 2006). Tuman, Moonie and Roth-Johnson, “The Administrative Prevalence of Autism

Spectrum Disorders...,” estimated a pooled time-series analysis and a latent growth curve model of ASD prevalence across all seventeen school districts in Nevada (from 1995 to 2004) and found that the upward trajectory of ASD was not associated with a statistically significant decline in prevalence of mental retardation, speech delays or learning disabilities; their results cast doubt on the validity of the diagnostic substitution hypothesis.

²⁰Raúl Calderón González, David Vallejo-Moreno, Aracely Santillán-Flores, Olga Rodríguez-Cavazos, Myrna Gutiérrez-Treviño, and Martha Díaz-Muraira, “Autismo infantil: Estudio clínico de 27 niños,” *Boletín Médico del Hospital Infantil de México* 45, no. 1 (1988): 12-17; Jorge Escotto-Morret, “El autismo infantil: Consideraciones actuales sobre el diagnóstico y tratamiento,” *Gaceta Médica de México* 127, No. 6 (1991): 501-505; Francisco Rogel-Ortiz, “Autismo,” *Gaceta Médica de México* 141, No. 2, (2004), 252-264. Sanua’s claim that there was little evidence of autism in Mexico and Latin America seems suspect. The specialists he contacted reported cases of “infantile psychosis” with clinical symptoms that are now considered part of the triad used in diagnoses of “atypical autism” or autism spectrum disorders (including pervasive developmental disorders). See Victor Sanua, “Is Infantile Autism a Universal Phenomenon?” *International Journal of Social Research* 30, No. 3 (1984): 163-177.

²¹Antonio Escobedo Aguirre, “Información sobre discapacidad en México en la última década del II milenio,” in *International Seminar on the Measurement of Disability* (New York: United Nations Statistics Division, 2001), 1-4.

²² Morales, “Bridge over Troubled Water” 114.

²³ The survey also found that autism was more prevalent than epilepsy and Down’s Syndrome.

²⁴ Santana and Santana, *An Introduction to Mexican Culture for Rehabilitation Service Providers*; B. Holzer, “Everyone Has Something to Give: Living with Disability in Jachitán,, Oaxaca, Mexico” in B. Holzer, A. Vreede, and G. Weigt (eds), *Disability in Different Cultures* (Germany: Transcript Verlag, 1999), 44-57.

²⁵ Jo Webber, Richard L. Simpson, and Judy K.C. Bentley, “Parents and Families of Children with Autism,” in Fine and Simpson (eds), *Collaboration with Parents and Families of Children and Youth with Exceptionalities* (Austin, TX: Pro-Ed, 2000), 303-324; B. Siegel, *The World of the Autistic Child* (New York: Oxford University Press, 1996); Lorna Wing, *Autistic Children* (Secaucus, NJ: Citadel, 1974).

²⁶ Oscar Alberto Araujo Campbell and Anna Silva Figuera Duarte, “Impacto del autismo en la familia: Percepción de los padres,” *Instituto Nacional de Neurología y Neurocirugía* 6, No. 1 (2001): 6-14. Araujo Campbell and Figuera Duarte noted that some rural families attributed autism to spirit possession and sought exorcism. In the present study, the research team observed something similar: In 2007, a grandmother from rural Mexico (living in the U.S.) gave a special medallion to her granddaughter to protect her from the “evil eye” that a child neighbor with autism might cast upon her. Even when rural communities find roles for people with mental disabilities and provide for their subsistence, studies suggest that everyday speech still betrays social stigmatization of disability, paternalistic attitudes, and subtle discrimination (for an account from Oaxaca, see Holzer, “Everybody Has Something to Give...”).

²⁷ Araujo Campbell and Figuera Duarte, “Impacto del autismo en la familia: Percepción de los padres,” *Noticieros Televisa*, “Autismo: Profundos silencios,” and Carlos Marcin, “Una visión (Dis)pareja,” *Ararú*, No. 1, (February/April 1993): 1-5.

²⁸ We recognize that there is a debate in the autism community about the underlying assumption that autism is a “problem” that requires treatment. One way of thinking about this is that treatment methods (with efficacy) do not extinguish autistic behaviors as much as they teach people with autism *an alternative, parallel way* of seeing the world; in other words, these methods can help build bridges of understanding and communication to the so-called “neurotypical” world from the world of autism. In the absence of a social policy that provides income to people with autism, possessing such alternative ways of understanding can facilitate the labor market integration, and economic independence, of people with autism.

²⁹ Araujo Campbell and Figuera Duarte, “Impacto del autismo en la familia: Percepción de los padres.”

³⁰ *Ibid*; In contrast to mothers in Mexico, Puerto Rican women (living in Puerto Rico) with children with disabilities tend to report greater feelings of satisfaction regarding support from

their extended family. See Maria E Reyes-Blanes, Vivian Correa, and Donald Bailey, "Perceived Needs of and Support for Puerto Rican Mothers of Young Children with Disabilities," *Topics in Early Childhood Special Education* 19, No. 1 (Spring 1999): 54-63.

³¹ For a more detailed discussion of gender and labor loads in the home in Latin America and their relationship to social constructions of *machismo* and *marianismo*, see Sylvia Chant, with Nikki Craske, *Gender in Latin America* (New Jersey: Rutgers University Press, 2003), and Santana and Santana, *An Introduction to Mexican Culture for Rehabilitation Service Providers*.

³² Eliseo Ramos Guajardo and Todd V. Fletcher, "Special Education and Education Reform in Mexico: Providing Quality Education to a Diverse Student Population," *European Journal of Special Needs Education* 13, No. 1 (1998), 37-38

³³ Dirección de Educación Especial, *Educacion con calidad* (Mexico, D.F.: DEE, 2003), 53-54, and Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial* *México, D.F.: SEP, 2006).

³⁴ Ramos Guajardo and Fletcher, "Special Education and Education Reform in Mexico," 36.

³⁵ Some information also drawn from an interview with director of training services for children with autism in the government agency *Dirección de Educación Especial*, Mexico City, July 2006; Dirección de Educación Especial, *Educacion con calidad*, 49-50, Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial*.

³⁶ Secretaria de Educación Pública, *Informe final de los resultados del programa para la atención de niños, niñas y jóvenes autistas en Cam Básico, Cam Laboral e USAER ciclo escolar 2004-2005* (México, D.F.: SEP, y Dirección de Educación Especial, Asociación Psicoanalítica de Orientación Lacaniana, 2006).

³⁷ These might include, for example, the Autism Diagnostic Observation Scale (ADOS), Childhood Autism Rating Scale (CARS), Autism Behavior Checklist (ABC), and other instruments used to assess speech, and gross and fine motor abilities. Prior to 1993, special education authorities used diagnostic instruments. See Eduardo Backhoff, Norma Larrazolo, and Hugo Ramano, "Children with Learning Disabilities in Mexico: The Behavioral Approach," in Artiles and Hallahan (eds), *Special Education in Latin America: Experiences and Issues* (Westport, CT: Praeger, 1995), 139-168.

³⁸ The fragmentary evidence suggests that, due to parental concern, some children receive diagnoses of ASD prior to entering public schools (see Raúl Calderón González et al, "Autismo infantil..." 13; Araujo Campbell and Figuera Duarte, "Impacto del autismo en la familia: Percepción de los padres," 8). Pediatricians, child psychologists or child psychiatrists providing such diagnoses might use reliable diagnostic instruments in the process of diagnostic evaluation. It is unclear whether such prior diagnoses are used by special education officials.

³⁹ Data on the structure and operations of USAERs across Mexico is highly variable. The most comprehensive, well-documented research has been completed on USAER and CAM programs in Federal District of Mexico City and Guanajuato (Eliseo Ramos Guajardo and Todd V. Fletcher, "Special Education and Education Reform in Mexico"; Todd Fletcher et al, "The Changing Paradigm of Special Education in Mexico"; Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial*, 19.

⁴⁰ Staff from previous programs, such as psycho-pedagogical centers and special education schools, have been integrated into USAERs and CAMs; Dirección de Educación Especial, *Educacion con calidad*, 49.

⁴¹ Morales, "Bridge over Troubled Water" 114; Dirección de Educación Especial, *Educacion con calidad*, 49.

⁴² Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial*, 19.

⁴³ Service delivery is divided between the "basic" CAM, which provides preschool and elementary education, and the "labor" CAM, which offers job training. Both programs cover children from 45 days after birth through age 22.

⁴⁴ Ramos Guajardo and Fletcher, "Special Education and Education Reform in Mexico," 37-38.

⁴⁵ Dirección de Educación Especial, *Educacion con calidad*, 49; Secretaria de Educación Pública, *Informe final de los resultados del programa para la atención de niños, niñas y jóvenes autistas en Cam Básico, Cam Laboral e USAER ciclo escolar 2004-2005*.

⁴⁶ By 2003, CAMs had replaced many other public programs that had offered early intervention and special education services prior to 1993, including special education schools, psycho-educational centers, and centers for early intervention (see Table 1 in the paper). For a discussion of previous early intervention and special education programs, see Backhoff, Larrazolo, and Ramano, "Children with Learning Disabilities in Mexico: The Behavioral Approach," and M. Gómez Palacio-Muñoz, "La educación especial en México," *Conesca* (1982): 2-10.

⁴⁷ Staff from the *Dirección de Educación Especial* in Mexico City suggested that most of the ASD children tend to be placed in CAMs (Interview, July 2006). Partial data from a training study they initiated in 2005, which only covered one USAER, one CAM, and one "labor" CAM (for young adults) indicates that 20 ASD students were enrolled in a "basic" CAM, while 3 were supported by a USAER team. See Secretaria de Educación Pública, *Informe final de los resultados del programa para la atención de niños, niñas y jóvenes autistas en Cam Básico, Cam Laboral e USAER ciclo escolar 2004-2005*.

⁴⁸ An internal report by education officials noted that although the Fox administration had pledged to close the gap in 2002 by allocating additional funds, only a small portion of the additional funds pledged in 2002 had been disbursed by 2006 (*La Jornada*, "Denuncian franco retrocenso de la educación especial en el país," July 31, 2006, 1). See also Todd Fletcher, and Carlos Dejud, Cynthia Klinger, and Isabel López Mariscal. 2003. "The Changing Paradigm of Special Education in Mexico: Voices from the Field," *Bilingual Research Journal* 27, no. 3: 409-30.

⁴⁹ Calculated from Dirección de Educación Especial, *Registro de Menores con Discapacidad* (México, D.F.: Secretaria de Educación, 1996); Secretaria de Educación Pública, *Orientaciones generales para el funcionamiento de los servicios de educación especial*, 25.

⁵⁰ The literature from Mexico also notes that parents of children with autism experience the same emotional responses as documented from studies in the U.S. Oscar Alberto Araujo Campbell and Anna Silva Figuera Duarte, "Impacto del autismo en la familia: Percepción de los padres. Noticieros Televisa, "Autismo: Profundos silencios," and Carlos Marcin, "Una visión (Dis)pareja,".

⁵¹ Secretaria de Educación Pública, *Programa Nacional para el fortalecimiento de la educación especial y de la integración educativa* 19.

⁵² This finding is compatible with the data in Table 1. Although there was a small growth in the number of CAMs and USAERs between 2002 and 2004, this was concentrated in the same geographical areas where coverage was present in 2002. Data from Instituto Nacional de Geografía, Economía y Informática (INEGI) show that from 2002 to 2004, the total number of children receiving special education services actually *decreased* from 436,207 to 379,273 (-13 percent net change), due partly to the closure of older special education schools that have not yet been replaced by the new institutions. Instituto Nacional de Geografía, Economía y Informática, *Anuario estadístico de los Estados Unidos Mexicanos* (Aguascalientes, México: INEGI, 2005). See also analysis and comments with staff in the Ministry of Education, as reported in *La Jornada*, "Fox presume plan de educación especial, pero cada vez meons ninos son atendidos," August 1, 2006, 1.

⁵³ Secretaria de Educación Pública, *Programa Nacional para el fortalecimiento de la educación especial y de la integración educativa* 19-20.

⁵⁴ Interview, January 15, 2001.

⁵⁵ Secretaria de Educación Pública, *Programa Nacional para el fortalecimiento de la educación especial y de la integración educativa* 20.

⁵⁶ Fletcher et al., "The Changing Paradigm of Special Education in Mexico: Voices from the Field."

⁵⁷ Interview September 1, 2000.

⁵⁸ *La Jornada*, "Denuncian franco retrocenso de la educación especial en el país."

⁵⁹ Attitudes of CAM staff reported in a 2006 survey were similar to those of USAER teams: 63 percent agreed that resources were insufficient to promote inclusion, 40 percent stated that teachers do not have sufficient help to attend to the needs of disabled students, and 46 percent agreed that there is little or no coordination among CAMs and other institutions. See *La Jornada*, "Fox presume plan de educación especial, pero cada vez meons ninos son atendidos."

⁶⁰ Depending on a child's level of performance, much of the literature calls for a one-to-one ratio or one staff person working in "very small" groups of no more than two students with autism and

one typically developing student. We found that in CAM no. 54 in Mexico City, six out of seven groups of children with disabilities that included students with autism had staff-to-student ratios that were above the recommended ratio (Secretaría de Educación Pública, *Informe final de los resultados del programa para la atención de niños, niñas y jóvenes autistas en Cam Básico, Cam Laboral e USAER ciclo escolar 2004-2005*, and *La Jornada*, “Fox presume plan de educación especial, pero cada vez meons ninos son atendidos.”

⁶¹ National Research Council, *Educating Children with Autism* (Washington: National Academy of Science Press, 2001).

⁶² Personal contact (via e-mail) with staff supervisors in the Lovaas Institute for Early Intervention, February 2006; JFK Partners, University of Colorado Health Services, February 2006; Rutgers University, February 2006; TEACCH Program, February 2006. Information on training was also drawn from an interview with director of training services for children with autism, *Dirección de Educación Especial*, Mexico City, (July 2006).

⁶³ Secretaría de Educación Pública, *Informe final de los resultados del programa para la atención de niños, niñas y jóvenes autistas en Cam Básico, Cam Laboral e USAER ciclo escolar 2004-2005*.

⁶⁴ See Donna Noyes-Grosser, Demie Lyons, Carole Holland, and Raymond Rmancyk, “Rationale and Methodology for Developing Guidelines for Early Intervention Services for Young Children with Disabilities,” *Infants and Young Children* 18, No. 2 (2005): 119-135; Jane Howard, Coleen Sparkman, Howard Cohen, Gina Green and Harold Stanislaw, “A Comparison of Intensive Behavior Analytic Treatment and Eclectic Treatments for Young Children With Autism,” *Research in Developmental Disabilities* 26 (2005): 359-383; National Research Council, *Educating Children with Autism*.

⁶⁵ For an impressionistic report of the effects of Lacanian treatments of children with autism in a private clinic, see Rosa Laura, Cantu “En búsqueda de un espacio humanizante: La escuela en el tratamiento del autismo y la psicosis infantil,” *Psicología Iberoamericana* 4, No. 1 (1996): 62-68.

⁶⁶ Contact with professional consultant, Mexico, September 2006.

⁶⁷ Indeed, if real GSP per capita (constant 2002 pesos) is modeled at the exogenous covariate and the number of clinics in each state and the federal district, as the outcome, the coefficient for real GSP per capita is $b = .25$ (standard error = $.06$, $p < .001$), which lends support to our interpretation of the data in Table 3. To be sure, this simple model may suffer from omitted variable bias (including the lack of state level prevalence data for autism in Mexico, which are not available).

⁶⁸ Baker “Children’s Disability Policy in a Global World,” 242.

⁶⁹ John P., Tuman, *Reshaping the North American Automobile Industry: Restructuring, Corporatism and Union Democracy in Mexico*, (London and New York: Routledge, 2003).

⁷⁰ Wage data for the automobile industry is collected from collective bargaining contracts from the archives of the Secretaría del Trabajo y Previsión Social, Coordinación General de Funcionarios Conciliadores, Mexico City, for the year 2004.

⁷¹ Araujo Campbell and Figuera Duarte, “Impacto del autismo en la familia: Percepción de los padres.”

⁷² Interview and contact with private psychologist who works with children with autism, Mexico, September 2006.

⁷³ Noyes-Grosser et al, “Rationale and Methodology for Developing Guidelines for Early Intervention Services for Young Children with Disabilities,” Howard et al, “A Comparison of Intensive Behavior Analytic Treatment and Eclectic Treatments for Young Children With Autism”; National Research Council, *Educating Children with Autism*.

⁷⁴ See review of studies in Lorenzo Pavone and Martino Ruggieri, “The Problem of Alternative Therapies in Autism,” in Coleman (ed), *The Neurobiology of Autism* (Oxford: Oxford University Press, 2005), 173-201.

⁷⁵ As measured by the incidence of protest or group meetings with government functionaries or legislators, based upon a search of two Mexican newspaper databases and websites of associations and groups representing the people with autism and others with mental disabilities. We also searched a variety of data bases in the U.S. and asked in interviews about meetings with party officials, bureaucrats and legislative representatives.

⁷⁶ See the review in Michelle Putnam, "Conceptualizing Disability: Developing a Framework for Political Disability Identity," *Journal of Disability Policy Studies* 16, No. 3 (2005): 188-198.

⁷⁷ Jeffrey A. Frieden, *Debt, Development and Democracy in Latin America* (Princeton: Princeton University Press, 2001).

⁷⁸ Without denying the possibility that "high functioning" adults with autism might be engaged politically, we assume that the core participants in groups advocating for change are likely to be parents of children with autism, along with other caregivers and stakeholders who provide services.

⁷⁹ Telephone interview, Mexico, January 5, 2001.

⁸⁰ This applies also to lone mothers who have been abandoned by their male partners or husbands. Given the significant time that these mothers must invest in the care of their children, it is unlikely that they would have sufficient time to be involved politically on a sustained basis.

⁸¹ Personal interview, Mexico, June 20, 1999.

⁸² Interview with professional consultant, Mexico, September 2006.

⁸³ Telephone interview, January 2001.

⁸⁴ See, e.g., Federación Latinoamericana de Autismo, *Estatutos*. (México, D.F.: FELAC, 2006) which specifically mention lobbying activities with government as a specific purpose of the group. See also Federación Latinoamericana de Autismo, "Objetivos," <<http://www.autismo.org.mx/index.html>> (accessed November 20, 2007). It is important to note that we include among the sample of smaller groups those associations that provide services reported in Table 3; many offer services and also seek to advocate for specific treatments. For this reason, we include these groups in the count of smaller advocacy organizations.

⁸⁵ On this point, see Putnam, "Conceptualizing Disability," 192.

⁸⁶ Although the SNTE has become independent from the PRI, it remains part of the umbrella of corporatist organizations that were created by the former regime. Within the union, however, there have been strong dissident movements. For a historical discussion, see Moria Lorena Cook, *Organizing Dissent: Unions, the State and the Democratic Teachers' Movement in Mexico* (University Park: Penn State University Press, 1996).

⁸⁷ Interview, Mexico, January 2002.

⁸⁸ Fletcher et al., "The Changing Paradigm of Special Education in Mexico: Voices from the Field."

⁸⁹ Tuman, *Reshaping the North American Automobile Industry*.

⁹⁰ Indeed, during the 1990s, the PRI organized the National Council on the Status of Disabled people and gave it official recognition as a way of limiting the influence of other autonomous popular organizations, including a large confederation of physically and mentally disabled. See Disability Awareness in Action, *Newsletter* 19, July 1-2, 1994: 1-2.

⁹¹ In keeping with this tradition, the PRI has in recent year held regular meeting with a PRI-affiliated union representing disabled workers, but not with other independent associations representing the disabled. See Partido Revolucionario Institucional, "Coordinación de prensa," 2006 (press release).

⁹² See, for example, Dana Lee Baker, "Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum," *Disability and Society* 21, No. 1 (2006): 15-29; Howard et al, "A Comparison of Intensive Behavior Analytic Treatment and Eclectic Treatments for Young Children With Autism"; National Research Council, *Educating Children with Autism*.

⁹³ See, e.g., Alfredo J. Artiles, Marg Caspo, and Eloisa G. de Lorenza, "Special Education for Students with Mild Disabilities: A Third World Perspective," in Artiles and Hallahan (eds), *Special Education in Latin America: Experiences and Issues* (Westport, CT: Praeger, 1995), 41-60; Neva Milicic, and Maria Pia Sius, "Children with Learning Disabilities in Chile: Strategies to Facilitate Integration," in Artiles and Hallahan (eds), *Special Education in Latin America: Experiences and Issues* (Westport, CT: Prager, 1995), 169-190; and Todd V. Fletcher and Margarita Martínez de Ramos, "From Mexico to Chile: Assessing the Advancement of Inclusive Education Practices in Two Latin American Republics," paper presented to the Inclusive and Supportive Education International Congress Inclusion: Celebrating Diversity?, Glasgow, Scotland (United Kingdom), August 2005.