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Abstract

In the past 50 years, Chile has transitioned from an underdeveloped to a developing country with important improvements in health indicators. The creation of a National Health Service with hospitals and health centers across the country, in addition to national health programs are the main factors behind this achievement. The decrease of infant mortality has led to an increase in the number of vulnerable infants with disorders that evolve to chronic conditions and compromised quality of life. In Chile, 12.9 % of the population has some degree of disability and 9 % has intellectual and developmental disability (IDD). Since 1994 several policies and laws have been enacted to protect children and adults with disabilities. Also, in 2008 Chile ratified the “Convention on the Rights of Persons with Disabilities” of the United Nations. During the past 10–20 years, governmental health programs for health promotion and protection of children’s rights have been created. These programs are aimed at underprivileged groups, including children with IDD. In Chile there are health surveillance programs for preterm children (PT) and for children with Down syndrome (DS). The growing group of children with autism spectrum disorder (ASD) needs more attention; at the time of writing, there is no special health program for them. Currently a National Health Program for Children has been developed including new recommendations for the care of children with IDD. However there are still inequities in the access to quality health care attention and therapies especially in regions far from the capital city. Some rehabilitation services are available for children with IDD, they mostly consist of physical and occupational therapy, and there is a big need of early intervention services.

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Introduction

Chile is a country with a population of nearly 17 million, with over 80 % living in urban areas, and over 6 million living in its capital city, Santiago [1]. In the past 60–70 years this country has gone through important changes, transitioning from an underdeveloped country to a developing nation with progressive economic growth. However, this growth has been uneven, being more notorious in the five main cities of the country. In the capital city Santiago there are more and better universities, more medical centers, more doctors per capita (with a wider variety of specialties), and more private clinics compared to the rest of the country. Chile is a long country with a main highway running through more than 3000 km from north to south. Various small towns in rural areas lack good schools and unpaved roads difficult access to quality health care. Furthermore, isolated towns lack basic resources such as laboratories, X-rays and some medical specialties.

Regarding health related issues, major improvements have been the result of the creation in 1952 of a National Health Service, with hospitals and health centers across the country [2]. Infant mortality rate is the clearest example of this health improvement, decreasing dramatically since the early 1940s (see Fig. 48.1), due to sanitary measures, followed by successful national

health programs focused at malnutrition and infectious disease control. Newborn mortality experienced an important decrease as a result of the creation of neonatal intensive care units (NICU) for at least one main hospital per region or province during the 1960s and training of neonatologists and obstetricians. Infant mortality is now 7.7 per 1,000 live births and neonatal mortality is 5.4 per 1,000 live births; even better health indicators can be found in privileged areas of Santiago. Chile, Costa Rica and Cuba share the best indicators of the region [2]. According to the Pan American Health Organization (PAHO), in the past two decades important decreases in infant mortality have taken place in the entire region, although there are notorious differences among some South American countries [3]. Overall life expectancy at birth has risen to 79 years [4], increasing concurrently with the economic growth of the country.

These higher survival rates have led to an increase in the number of infants and children with congenital or acquired disorders, evolving to chronic conditions characterized by lack of independence and compromised quality of life [5]. This group of children and adolescents are characterized as having special health care needs (CSHCN), a term first coined by McPherson in 1998 [6].

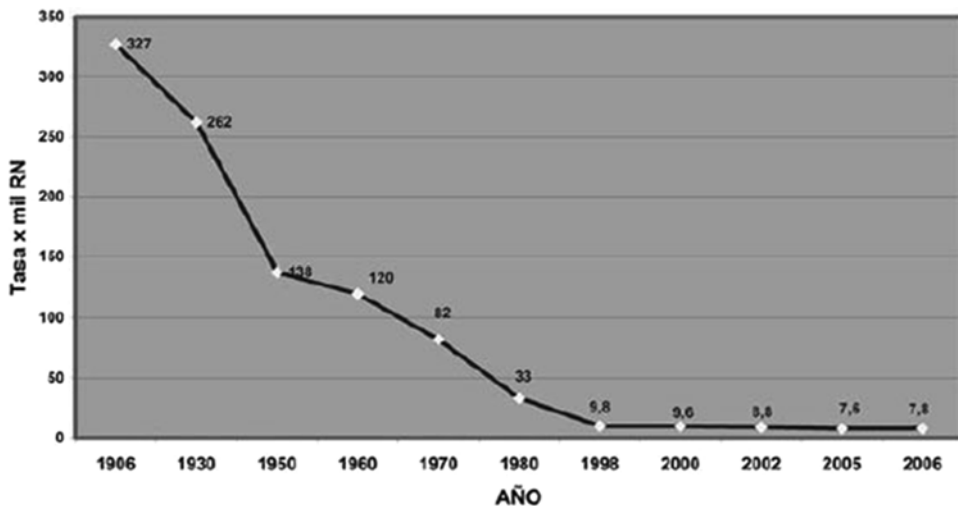


Fig. 48.1 Infant mortality rate in Chile. 1906–2006 (Source: Rev ChilPediatr 2009;80(5):399–406)

In 2008, the Chilean Pediatric Society (SOCHIPE, from the Spanish Sociedad Chilena de Pediatría) decided to incorporate the concept of CSHCN, to replace the previous concept of “chronic diseases of childhood”, creating the Committee on Children and Adolescents with Special Health Care Needs (NANEAS). This term is used to describe “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” [7], including children with intellectual and developmental disabilities (IDD). The focus of this committee is to orient health care toward the child’s special needs, responding to the common problems of children with these chronic conditions: need of multiple or long term medications, need of support technology, specialized nutritional support, special health care services and therapy (physical, occupational or speech therapy). There are limited experiences of CSHCN programs in Latin America, and unfortunately there is no epidemiological data, or description of their characteristics in this region. In Chile there is only one published study in hospitalized patients, where the CSHCN group accounted for 60 % of hospital discharges in children under 15 years of age [8].

In 2004 the first national survey of disability took place and reported that 12.9 % of Chileans live with some degree of disability, 5.7 % were under 15 years of age, and intellectual and developmental disability was present in 9 %. One in every three households in Chile has at least one family member with a disability [9]. The second survey of health and quality of life in Chile (ENCAVI 2006) [10], carried out with self-responding questionnaires, reported that 15.7 % of children younger than 15 years of age have a chronic respiratory disease; 8 % have a visual impairment and 5.6 % were born prematurely. Finally, according to the latest data reported in the 2012 Chilean Census [1], there are more than 2 million people with disabilities in Chile, which corresponds to the 12.7 % of the total population, 17.6 % of them have an intellectual, mental or psychiatric disability and 5.6 % of them are children under 5 years of age.

In 1994 the “Policies for Complete Social Inclusion of Persons with Disabilities”, Law No 19,284, was enacted in Chile, becoming the first law to protect the rights of citizens with IDD [11]. Since then, important changes in public policy have taken place, creating public awareness regarding disabilities and improving accessibility to buildings and public transportation. In 2002 Chile signed the “Inter-American Convention on the Elimination of all Forms of Discrimination against persons with Disabilities” that ensured the non-discrimination and equal opportunities of people with disabilities [12]. In 2008 Chile also ratified the “Convention on the rights of persons with disabilities” of the United Nations [13]. Unfortunately there are still many unsatisfied demands, particularly in terms of access to health care, education, employment and better quality of life for children and adults with disabilities [14].

In 2010 the “Policies on equal opportunities and social inclusion of persons with disabilities” law (Law No 20, 422) was enacted, orienting public policy towards a social model, shifting from a medical centered model of care to a biopsychosocial approach, respecting the rights and promoting the independence and autonomy of adults and children with disabilities [15]. New public policies for people with disabilities were recently published (National Policy for Social Inclusion of Persons with Disabilities 2013–2020) [16], this document’s objective is to enhance the culture of respect and protection of rights of people with disabilities, promoting their participation in civic, educational, economic, social and cultural life, based on the principles of equal opportunity, responsibility, respect for diversity, autonomy, social dialogue with full social inclusion. This is a good starting point.

Health Care and Government Benefits for Children with IDD

Historically, health care surveillance for children with IDD had taken place in hospitals or specialized health centers, was delivered by specialized professionals, with the knowledge and the resources regarding complex health care. This,

together with a strong bond between patients, families and the healthcare team, kept health care located mainly in hospitals for a long time. This meant that children with IDD and their families were separated from their local health care centers, losing benefits of Primary Care Services (PCS). In Chile, public primary care is based on Family Health Care Centers, which offer health care and follow-up of families based on a biopsychosocial model, with a holistic approach, facilitating continuity of care, which is essential for children with IDD.

In 2013 the Chilean Ministry of Health published a new National Health Program for Children, including a special program for CHSCN [17], classifying them according to the complexity of their needs. From 2014, children with minor complexity, those who are medically stable and those whose family have the skills needed to cope with the care of their child, can be comprehensively treated in their local Primary Care centers. This new program will allow better planning of health care for this group. However, the challenge will be to develop an effective and efficient liaison with pediatric specialists at a secondary level and hospital medical teams at a tertiary level.

There are also other health programs created for the promotion of a healthy life style, child development and protection of children's rights:

- AUGE Plan: This program guarantees universal access to health care for particular diseases [18]. It has been implemented gradually since 2005, guaranteeing access, opportunity and quality of care, financial coverage and treatment based on Guidelines created for each disease. The AUGE Plan at the moment covers 80 diseases, regardless of the type of health insurance and whether the patient is affiliated to the public or private health system.
- Chile Grows With You Program (from the Spanish Chile Crece Contigo): This program aims at comprehensive protection for children. It seeks to accompany, protect and give full support to all children and their families, offering additional services to those at greater risk or vulnerability. This is part of the Interdisciplinary Social Protection System, created in 2009 (Law 20,379) [19].
- National Disability Service: SENADIS (from the Spanish Servicio Nacional de la Discapacidad), created in 2010, to promote equal opportunities, social inclusion and respect for rights, social participation and accessibility for people with disabilities and their families [19], in accordance with the “International Convention on the Rights of Persons with Disabilities” of the United Nations [13].
- CSHCN health care programs for secondary care: In the past decade a few public and private hospitals have created CSHCN health care programs. Some examples of this are the CSHCN Program at the Pontificia Universidad Catolica de Chile's Health Network, which is a private teaching center, and at the Sotero del Rio Hospital, which belongs to the public health system. These programs provide comprehensive services to complex patients offering a multidisciplinary approach. At present there is no national network in the country that completely satisfies CSHCN.

The task now at hand is to implement the new 2013 National Health Care Program for Children, with special emphasis in CSHCN, training health care professionals throughout the country.

Rehabilitation Services for Children with IDD

At present, only a few hospitals in the metropolitan area have comprehensive rehabilitation centers that offer services to children with disabilities. These public services were at first based on physical therapy and in the past years, multidisciplinary teams have been organized, including speech and language stimulation, treatment for feeding problems, mental health services and early intervention programs. However, most of these services are in the capital city. Only 51 % of the counties of the regions have some type of rehabilitation service: there are only 143 Community Rehabilitation Centers and 96

Integral Rehabilitation Centers [14] in the whole country.

Teleton Institution is the main rehabilitation center of Chile, with centers all over the country. It offers comprehensive treatment for children and adults particularly with motor impairments. This institution is financed by donations. In spite of the successful achievements of this center, the demands for therapies are increasing every year, generating long waiting lists. At first, Teleton Institute received only children and adults with motor disabilities; however in the past years they are also treating children with IDD, such as establishing a Down Syndrome Program. Children with IDD need other services such as Early Intervention, support with maternal-infant bonding, feeding therapy and therapies oriented to independent living. Special therapists are needed to fulfill the needs of children with IDD.

Private rehabilitation centers also exist in Chile, some of them associated to university hospitals, such as the Neuro-rehabilitation Program of the Pontificia Universidad Catolica de Chile's Health Network. These private centers tend to be located in the more privileged areas of Santiago, are quite expensive and only a few of them offer special services for children with IDD.

Health Programs

Children with IDD have increased in number due to improvements in life expectancy of vulnerable children, like preterm infants, children with genetic disorders, or children with other causes of developmental delay. In this chapter we will review the special health programs that exist in Chile for preterm infants, children with Down syndrome (DS) and with Autism Spectrum Disorder (ASD).

Preterm Health Care

The survival rate for newborns, particularly preterm infants has increased in the past decades due to improvements in newborn health care and technology, also to the increase in hospital deliv-

eries, which account for 90 % of births; leading to overall improved care of newborns.

There are around 250,000 births each year in Chile; 1–2 % are preterm (PT), under 32 weeks of gestation or under 1500 g (very low birth weight (VLBW)) [2, 20]. During the late 1960s, neonatal intensive care units (NICU) were created throughout the country. It took over 20 years to develop a national network of preterm infant follow-up programs, consolidating in the year 2000 when the first national guidelines were published [21]. This effort has had a significant effect in improving the outcomes of preterm infants in the whole country. The overall survival rate (at discharge) for this group is now 75 % [22], even though considerable disparities remain among outcomes in different regions and hospitals of the country. The metropolitan area's hospitals, where the capital Santiago is located, share the best numbers with some private clinics. The Pontificia Universidad Catolica de Chile's Health Network has one of the best survival rates of the country, reaching 85–90 %, attributed to a higher nurse-newborn ratio, in comparison to other units in the country, and to formal training in neonatal care of their health professionals [23].

There are new national guidelines for preterm follow-up that include home visits while the newborn is still in the NICU; followed up by multi-disciplinary care after discharge, including visits to primary care centers alternating with secondary level specialists. In the primary care level, children receive nutritional assessment, developmental screening and Early Intervention Services [17].

In spite of technological advances in neonatal care, preterm infants are especially vulnerable and at risk for various complications. Many of these can result in developmental delay, requiring long term physical, occupational and speech therapy. Unfortunately, access to these therapies is not always available, especially in regions far from Santiago. In the public health system, a few physical therapy centers exist, but various unmet needs remain.

Permanent hearing impairment has been reported in 3 % of preterm infants born in public hospitals in Chile [24]; most of these children

will develop a significant language delay, unless treated before 6 months corrected age. Since 2005 there is a national program for early detection of hearing impairment in preterm infants, including treatment with assistive listening devices when needed [25]. This has been a major improvement for preterm infants, particularly for children from underprivileged families. Nevertheless national coverage is still limited, not more than 60 % of preterm infants are screened on time.

Retinopathy of prematurity (ROP) is an important cause of visual impairment. In Chile, between 2000 and 2005, 23 % of preterm infants developed ROP, 13 % required surgical treatment [22]. Twenty four percent of visually impaired children under 10 years of age were preterm [26]. A special national program for children with retinopathy exists since 2009, offering early diagnosis and treatment, follow-up and visual devices when needed.

Cerebral palsy (CP) is one of the more serious motor consequences of prematurity. In Chile, between 2000 and 2005, the public preterm newborn follow-up network reported 10 % of CP among survivors, half of them with IDD. Severe intracerebral hemorrhage was present in 13 % of preterm infants of this study and was closely related to death [22]. Survivors had milder degrees of cerebral hemorrhage, and therefore milder sequelae.

A recent report of children with CP studied at Pontificia Universidad Catolica de Chile showed that 53 % of tetra paretic patients with CP had severe IDD and 14 % had mild IDD [27]. These children benefit from a multidisciplinary approach with physical and occupational therapy, speech therapy, neurologists, pediatric surgeons, orthopedic surgeons and other specialists. Their families need psychological support because it is a stressful and time consuming disorder. There is no national program for treating children with CP. Most of them are referred to Teleton and other rehabilitation centers. These centers were at first focused mainly on physical therapy, in reducing muscular contractions and deformations. In the past years attention is also given to their cognitive development.

Another significant consequence of prematurity is bronchopulmonary dysplasia (BPD). The overall incidence is 20-35 %, rising to 60 % in preterm infants under 1000 g. In Chile, between 2000 and 2005, 15 % of infants with BPD died before 12 months corrected age, and 9 % of survivors with severe BPD were children with IDD [28]. A special program for BPD patients exists [29], which offers treatment with home oxygen and respiratory therapy when needed.

Preterm infants in Chile are usually discharged with only 34–35 weeks of gestational age and/or when they approach 2000 g of weight; they are immature, and undernourished. Although breast feeding is highly recommended for preterm infants, it does not always meet the nutritional needs of the infant. Several reports recommend special preterm formulas after discharge for reassuring catch-up growth. Moreover, adequate post-discharge growth of preterm infants has been associated to better developmental outcomes. In Chile, in the year 2000 a national feeding program for preterm infants was created, aiming at benefiting underprivileged families that couldn't afford this special milk; it includes special preterm formula for the first 6 months of corrected age, and follow-up formula from 6 to 12 months of corrected age [30]. After 5 years of this program, a study showed that children fed with post-discharge formula for 6 months or more, had fewer metabolic complications, compared to infants fed with post-discharge formula only during their hospital stay [31]. No differences were found regarding developmental outcomes.

In terms of intellectual development, speech and language delay is present in over 28 % of preterm infants [32]. In spite of this, accessibility to speech therapy is limited for most children, especially in those under 3 years of age.

Early Intervention is beneficial in the developmental progress of preterm infants. With the creation of Chile Grows With You program in 2005, health centers started new and rewarding experiences. One of the activities of this program is called Nobody is perfect and is aimed at children with developmental delay, especially those with IDD.

In the past 10 years, the major contributions of the national follow-up program for preterm infants have been its feeding program and early detection of hearing impairment and ROP, reducing some of the conditions associated with developmental delay in this group of children. However, an additional effort is needed to achieve better long term outcomes. Preterm children have lower IQ scores and more learning difficulties than their peers born at term, requiring more support [33]. To ensure optimal results, preterm infants with IDD should begin Early Intervention as soon as they are discharged and should have access to a comprehensive follow-up program. In the long run an additional effort is necessary to improve the educational level of parents, and to reduce inequities, so all parents can have the intellectual tools to promote the best development of their children. The new National Health Program for Children includes home visits for preterm infants and Early Intervention Programs that need to be implemented in all regions of the country.

Health Care for Children and Adolescents with Down Syndrome

According to the records of the Latin American Collaborative Study of Congenital Malformations, ECLAMC, (from the Spanish Estudio Colaborativo Latino Americano de Malformaciones Congenitas), the prevalence of children with DS in Chile has increased during the past decades, with rate of 2.4 per 1,000 live births [34]. Every year in Chile, between 500 and 600 children with DS are born, resulting in a significant population. Birth rate for DS is significantly higher in Chile, compared with other countries in Latin America (2.4 per 1,000 vs 1.8 per 1,000 live births). This increased incidence in DS is concurrent with increasing maternal age, reported as one newborn with DS for every 33 births in women over 39 years of age [35]. Other factors have also contributed to this prevalence, such as the fact that in Chile abortion is illegal and improvements in perinatal health indicators result in improvement in outcome.

Children with DS have common physical findings, medical conditions and variable cognitive impairment because of the presence of the extra chromosome 21. Therefore, they require special health care aimed at prevention, early diagnosis, and treatment of the different health conditions. Infants with DS should participate in Early Intervention Programs and varied developmental stimuli throughout their lifetime, aiming at optimal achievement of their potential. In addition to this, organized health supervision has a positive impact on the psychosocial well being of children with DS and their families. Special health care programs for children with DS exist in Chile in some pediatric public hospitals. In the private health system, Pontificia Universidad Catolica de Chile's Health Network has become a national leader; offering a comprehensive program of health surveillance spanning the prenatal period to adult life. During pregnancy, families expecting a child with DS receive specialized care; in the case of a postnatal diagnosis, specialized pediatric care and Early Intervention Services are offered. There is available a recently created Program for adults with DS, with a coordinated transition from pediatric to adulthood health care. There are no national guidelines for health supervision for children with DS in Chile, however, international recommendations [36, 37] have been adapted in 2013 for the Chilean population [38].

The main challenge for improving the quality of life of a person with DS in Chile is universal access to Early Intervention Services, an individualized education plan, adequate vocational training, employment opportunities and independent living. Today, there are large inequities in access to these opportunities, not only because of the socioeconomic level of the family, but also the geographical locations, since the greatest opportunities in terms of Early Intervention Services are still centralized in the capital city.

Health Care for Autism Spectrum Disorders

ASD have increased worldwide in the past years, as much as 1 in 88 children in the USA have been

identified with an ASD [39]. Early detection has an important impact on prognosis; therefore the AAP recommends the use of screening tools at the age of 18–24 months of age for all children. In Chile there are no prevalence data available; screening tools are not used routinely in well child visits. In the past year, an ongoing study between members of the Department of Pediatrics of Pontificia Universidad Catolica de Chile and the Southeast Pediatric Environmental Health Specialty Unit at Emory University is taking place. This study uses the Modified Checklist for Autism in Toddlers (M-CHAT) as a screening tool for early diagnosis of ASD. The questionnaire is answered by caretakers of children between 18 and 24 months of age, who attend two different health care centers, one of them in an underprivileged community. The study is still recruiting patients; therefore there are no final results available at the moment. This study so far has raised awareness on ASD amongst our health professionals, and we are sure that it will contribute to improve the early diagnosis in our community by incorporating this tool into everyday practice. This is the first step in the process of developing a national program based on screening, early identification, and adequate treatment for children with ASD.

We believe that a multidisciplinary approach to children with ASD, increases socially appropriate behavior and decreases the severity and/or emergence of challenging behaviors, thus promoting a quality of life for children and their families.

Health Care Transition to Adulthood for CSHCN

During the past decades an increasing number of CSHCN are reaching adulthood in part due to the decline of infant mortality and improvements in health care with resultant increased life expectancy. Nevertheless, many of these adults with special needs are still treated by pediatricians or pediatric subspecialists, without considering that they need the care appropriate for an adult.

Pediatricians and the families continue to have difficulties in promoting independence for

CSHCN, not taking into account their needs for independence as an adult, for example, at a basic level, learning how to make their own decisions, in order to plan a healthy transition to adult life. All CSHCN health programs should include an organized plan for transition, acknowledging that it is often difficult for the patient, for the family and also for the health care team.

According to the recommendations of SOCHIPE's NANEAS committee, in order to achieve a healthy transition to adult health care it is important to plan in advance with the patient and family, preparing them for this process. It is also necessary to ensure proper coordination between pediatric and adult specialists [40]. However, few formal experiences of successful transition to adult health care exist in Chile. For certain chronic conditions, such as cystic fibrosis, there are formal transition programs in the public health system, but none of these exist for persons with IDD.

Most adults with IDD in Chile have not had access to career training nor employment opportunities. The majority are financially dependent on their family, with whom they usually live. However, limited experiences do exist. Two universities, both private, have career training for adults IDD, and a few employers offer supported employment opportunities for them. Also, some group homes for supported independent living exist for adults with IDD [www.coanil.cl]. Most of these experiences depend on non-governmental organizations and private foundations, and are located mostly in Santiago.

In 2013 the Health Care Program for Adults with Down syndrome began at the Pontificia Universidad Catolica de Chile's Health Network, offering follow up with a multidisciplinary team, in coordination with the corresponding pediatric Program. At present approximately 40 adults with Down syndrome participate in the program.

Conclusions

Chile in the past 30–40 years has gone through important economic growth and health care improvements; however, there are still inequities in terms of access to medical attention. Children

and adults with IDD are a growing population due to high survival rates of vulnerable children; they need access to the best medical attention and to Early Intervention Programs in order to achieve their full potential.

In the past 20 years, several laws and policies have been enacted to protect children and adults with IDD, shifting various paradigms of society.

Health programs have been developed for protecting the most vulnerable children. Preterm infants have access to special feeding programs and to special treatments for specific conditions such as retinopathy and bronchopulmonary dysplasia. Children and adults with DS also have access to special health surveillance programs addressing their particular needs.

To date, the main challenge in Chile is to increase awareness regarding the inclusion of adults with IDD to society, creating more opportunities for the development of skills necessary for employment and independent living.

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