# Clinical Abnormalities, Early Intervention Program of Down Syndrome Children: Queen Sirikit National Institute of Child Health Experience

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***Objective:*** *Queen Sirikit National Institute of Child Health is a tertiary institute of children in Thailand, where early intervention programs have been provided since 1990 by multidisciplinary approach especially in Down syndrome children. This aim of the present study is to follow the impact of early intervention on the outcome of Down syndrome children. The school attendance number of Down syndrome children was compared between regular early intervention and non-regular early intervention.*

***Material and Method:*** *The present study group consists of 210 Down syndrome children who attended early intervention programs at Queen Sirikit National Institute of Child Health between June 2008 and January 2012. Data include clinical features, school attendance developmental quotient (DQ) at 3 years of age using Capute Scales Cognitive Adaptive Test/Scale (CAT/CLAMS). Developmental milestones have been recorded as to the time of appearance of gross motor, fine motor, language, personal-social development compared to those non-regular intervention patients.*

***Results:*** *Of 210 Down syndrome children, 117 were boys and 93 were girls. About 87% received regular intervention, 68% attended speech training. Mean DQ at 3 years of age was 65. Of the 184 children who still did follow-up at developmental department, 124 children (59%) attended school: mainstream school children 78 (63%) and special school children 46 (37%). The mean age at entrance to school was 5.8$\pm$1.4 years. The school attendance was correlated with maternal education and regular early intervention attendance.*

***Conclusion:*** *Regular early intervention starts have proven to have a positive effect on development. The school attendance number of Down syndrome children receiving regular early intervention was statistically and significantly higher than the number of Down syndrome children receiving non-regular early intervention was. School attendance correlated with maternal education and attended regularly early intervention. Regular early intervention together with maternal education are contributing factors influencing school attendance in Down syndrome children in the present study.*

***Keywords:*** *Down syndrome, Early intervention, School attendance*

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Down syndrome[1,2] is a common chromosome abnormality that causes development delays in children with an incidence of 1:600-800 live births. It is also associated with other abnormalities such as congenital heart diseases (30-40%), abnormal digestion (10-15%), abnormality of endocrine gland (2-15%), etc. Previous study[6-8] have shown that most of Down syndrome children have delayed development. However early stimulation[3,5-7] starting early in the first year of life has been described as having a beneficial effect on development. Early Intervention programs and multidisciplinary approach[2,3,5-7] are designed to help young Down syndrome children between birth and three years old of age to maximize development. In Thailand[7-10], despite basic medical care and nationwide basic pregnancy screening, early intervention programs for special groups of children is limited only to specific developmental units. At Queen Sirikit National Institute of Child Health, early stimulation programs have been provided since 1990.

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The authors have had the opportunity to provide multidisciplinary medical care and early intervention in Down syndrome. The authors performed a prospective study of the children with Down syndrome for the purpose of studying the clinical features, early stimulation and school attendance of Down syndrome children receiving early intervention at developmental department.

**Objectives**

The authors performed a prospective study of the children with Down syndrome at Queen Sirikit National Institute of Child Health. The first aim studied clinical features, the percentage of children receiving regular early stimulation and non-regular early intervention. The second aim was to study the mean ages of times of appearance of developmental levels and school attendance numbers of Down syndrome children to compare them between regular early intervention and non-regular early intervention. The third aim was to perform a review of school attendance factors.

**Material and Method**

This prospective study was conducted with the inclusion criteria being children diagnosed with Down syndrome (DS) who attended early stimulation at Queen Sirikit Institute of Child Health from June 2008 to January 2012, who received chromosome study in the 0-3 years of age group. Exclusion criteria was Down syndrome children who did not receive early intervention from developmental department. The children who attended the early stimulation program at least 8 times annually were classified regular early intervention, less than 8 times annually were classified as non-regular intervention. Demographics data were collected including general information. The child developmental quotient (DQ) was evaluated by Capute Scales Cognitive Adaptive Test/Scale (CAT/CLAM)[5]. The Capute Scale are designed to assess the two streams of cognitive development, longitudinal language pathways based on sequential milestones languages (CLAMS) and visual motor solving skills (CAT). The scores were divided by the child's chronological age to determine the DQ. The same developmental pediatrician conducted all development tests of Down syndrome children. Concerning associated congenital anomalies[2,6-8], all DS children were evaluated for congenital heart diseases, gastrointestinal anomalies, and hypothyroidism by pediatricians. Children with suspected congenital heart disease were referred to pediatric cardiologists and those with suspected gastrointestinal anomalies were referred to gastroenterologists and pediatric surgeons. Thyroid function test[4,8,9] were routinely performed in all Down syndrome children and all individuals were referred to pediatric endocrinologists if the results were abnormal. Vision and hearing[2-5,7] assessments were also done in all DS children. A geneticist gave genetic counseling to the families at the first visit in the Genetic clinic. All families were routinely advised to attend the speech-training program at the age of about 10-18 months. Clinical features of Down syndrome children were recorded. The data of developmental milestones included the ages of appearance of gross motor, fine motor, language and personal-social development. The mean ages at the time of appearance of developmental landmarks and number of days of school attendance in children with DS receiving regular early intervention as compared to those who received non-regular intervention.

A developmental nurse at Queen Sirikit National Institute of Child Health provided the early stimulation program. The stimulation program involved stimulating the development of gross motor and fine motor skills, assisting with sucking, swallowing, feeding problems and self- help skills. At each visit, the patients were evaluated for developmental milestones by the pediatrician. The parents of children aged over 5 years were asked for school attendance records of their children. The school attendance factoring was performed.

Means $\pm$ standard deviation, ranges, numbers, and percentages were used for descriptive statistics. Frequency tables and percentages were shown to describe the prevalence and types of disorder. Description statistics and 95% confidence interval, Chi-square test, unpaired t-test, One-sample t-test were applied to test the significance of different values with $p<0.05$ was considered statistically significant.

The Ethics committee of Queen Sirikit National Institute of Child Health approved this study.

**Results**

A total of 285 Down syndrome children received the treatment at Queen Sirikit National Institute of Child Health from June 2008 to January 2012. Two hundred and ten children 117 were boys and 93 girls received the early intervention from development unit, of which 184 (87.6%) received regular early intervention. One hundred and seventeen children (55.8%) received their regular intervention before the age of 3 months

while 93 children (44.2%) received thus first intervention after 3 months of age. One hundred and thirteen children (62.1%) were born in hospitals in Bangkok and 97 children (37.9%) were born in provincial hospitals. All Down syndrome children received chromosome anomalies, pediatric cardiologists evaluation and an echocardiogram. Congenital heart diseases were found in 156 children (74%). Thyroid function tests were evaluated in all Down syndrome children and found to be abnormal in 88 (42%). Other diseases were found in Down syndrome children other than congenital heart diseases and endocrine disease are shown in Table 1. The mean maternal age at that time of the child's birth was 28 years whereas the mean paternal age the time of the child's birth was 32 years. Regarding number of siblings, single child 70 children (38%), had one or two siblings in 76 cases (42%) while 34 children (20%) had three or more siblings. One hundred eighty-four cases (87.6%) and 150 (68.2%) attended speech-training programs. All the DS children had developmental quotient (DQ) evaluation and had an average score of 65 (mild mental retardation). All of Down syndrome children had recorded the time of appearance of gross and fine motor, language and personal social development. The mean ages of time of appearance of developmental landmarks in children with Down syndrome who received regular, early intervention were significantly earlier compared to those who had non-regular early intervention are shown in Table 2. Number of DS children who attended school was significantly higher in the regular, early intervention group 124 (59%) compared to 6 (2.8%) in non-regular early intervention group as shown in Table 3. Seventy-eight children (63%) attended regular schools while 46 children (37%) attended special schools. The mean age at school admission was 5.8$\pm$1.4 years. The school attendance correlated significantly with maternal education and attending regular, early intervention programs as shown in Table 4.

**Table 1.** Prevalence and types of disorders found in Down syndrome children

| Type of disorders | Patients n=210 | % |
|---|---|---|
| Congenital heart diseases | 156 | 74 |
| GI Anomaly | 45 | 21.4 |
| Endocrine Anomaly | 88 | 42 |
| Visual Impairment | 86 | 40.9 |
| Hearing Impairment | 48 | 22.8 |
| Globally delayed development | 210 | 100 |

## Discussion

The results of the present study revealed that all Down syndrome individuals had developmental delays with an average developmental quotient (DQ) of 65 which is close to the study of Ponsawan et al which showed the average DQ of 64. The results of the present study revealed that average age of fathers was 32 years, average age of mothers was 28 years old, and most of Down syndrome children were either the first or second born in the family. After having the affected individuals, most of parents decided to have no more children. Of the DS children who received early intervention from the development department at QSNICH, 184 (87.6%) received regular early intervention and 26 children (12.4%) received non-regular intervention. This could be because some parents preferred early intervention at the hospital nearby their hometown: composition-117 boys, 93 girls. The average age at first intervention was 3.4 months. One hundred and thirteen (62.1%) were born in hospitals in Bangkok. The incidence of associated diseases in Down syndrome children in the present study was about the same percentage as previously reported[2-4,11,15] in both Thailand and western countries except for visual impairment and hearing loss that was lower in the present report. The common problems associated with DS were global delayed development in 210 children (100%), congenital heart disease 156 children (74%), abnormality of endocrine gland 88 (42%) and abnormality of gastrointestinal tract (14.7%). In this study, there was a high percentage (74%) of congenital heart disease because QSNICH is tertiary institute with a large cardiology unit.

All individuals with Down syndrome have developmental delay and mental retardation[8,10,12,13] which are cause for parental concern. The specific causes[1,3,9-12] of developmental delays and mental retardation have not been clearly documented, although a decreased number of cortical neurons, malformed dendritritic network and decreased lamination of the cortex have been postulated. Up to the present[4,6,13-16], no pharmacological therapy has shown to have any beneficial effect. Early intervention[4,9,11,13-15], starting in the first year of life has been proven to have a positive effect on development. Early intervention programs[4,5,7-9], serve young children between birth and three years of age who have Down syndrome. Through these programs, children have access to a range of services designed

**Table 2.** Mean age (months) ± SD of time of appearance of developmental milestones in children with Down syndrome receiving regular early intervention compared to those nonregular early intervention

| Developmental milestones | Regular early intervention (n = 184) | Non-regular intervention (n = 36) | *p*-value (<0.05) |
|---|---|---|---|
| Gross motor | | | |
| Roll over | 5.0±1.4 | 7.4±1.6 | 0.01 |
| Sit unsupported | 8±22.2 | 17±1.2 | 0.03 |
| Stand up | 16.4±5.4 | 29±6.3 | 0.04 |
| Walk alone | 24±1.8 | 34±1.8 | 0.01 |
| Fine motor | | | |
| Passes object from hand to hand | 8.3±6.3 | 17±1.5 | 0.03 |
| Puts cube in cup | 17±8.2 | 22±5.4 | 0.02 |
| Scribble | 15±9.3 | 22±3.8 | 0.04 |
| Builds a tower of two cubes | 20±8.3 | 33±5.6 | 0.01 |
| Personal social | | | |
| Feeds self | 10±1.8 | 22±2.1 | 0.002 |
| Plays pat a cake | 14±1.2 | 22±1.8 | 0.003 |
| Use spoon or fork | 22±1.6 | 33±1.8 | 0.001 |
| Dresses self partially | 64±5.6 | 76±2.2 | 0.02 |
| Language | Speech therapy (n = 150) | Non speech therapy (n = 70) | |
| Turn to sound of voice | 6±3.4 | 14±2.2 | 0.04 |
| Say dada ,ma-ma specific | 13±5.2 | 26±2.3 | 0.03 |
| Say at least one meaning word | 15±3.3 | 36±3.8 | 0.002 |
| Say Combined words | 25±8.2 | 76±1.9 | 0.001 |

**Table 3.** Factors influencing school attendance

| Early intervention (n = 210) | Number of school attendance (n = 130) | Number of non school attendance (n = 80) | *p*-value <0.05 |
|---|---|---|---|
| Regular early intervention (n = 184) (87.6%) | 124 (59%) | 50 (23.4%) | 0.02 |
| Non-regular early intervention (n = 26) (12.4%) | 6 (2.8%) | 30 (13.3%) | <0.01 |

**Table 4.** Number of school attendance

| Factors | *p*-value <0.05 | 95% confidence interval |
|---|---|---|
| Maternal education | 0.03 | 1.89-28.2 |
| Paternal education | 0.58 | 0.50-1.98 |
| Receiving regular early intervention | 0.02 | 1.90-29.0 |
| Receiving speech therapy | 0.21 | 2.38-33.2 |

to help them reach their full potential, such as speech therapies[13,14] and early stimulation therapies. As shown in the present study, children receiving regular early intervention attained their developmental milestones significantly earlier than those receiving non-regular intervention in all developmental domains. The result were similar for DS who received the speech-training program[14,16]. Early intervention is recom-mended in

QSNICH, with in the first 3 months of life to facilitate bonding between parents and DS children. Motor development for children with Down syndrome is usually delayed significantly from hypotonia. However, the basic motor skills are achieved by children with Down syndrome in mostly the same order. This is illustrated by the examples given in Table 2. The group pattern, focused on social-emotional development, which concentrates the parents to strengthen the family unit. The promotion of early intervention in DS children at QSNICH by created a group of parents pararell with group of Down syndrome children are win-win situation because a group of parents will help for empowerment[11-13] family. In the present study verifies the importance of regular early intervention. The influence of environmental factors is attainment of developmental milestones. Down syndrome children who attended the speech therapy[5,14,15] program can improve the children's communication skills and use language more effectively. DS children can understand language and usually want to communicate before they can actually speak. Speech therapist[14,16,20] can help a child use alternate means of communication until he or she learns to speak. In the present study mean age of school admission was 5.8±1.4 years. School attendance was correlated with maternal education and regular early intervention which was similar what was previously reported[21]. Regarding the number of days of school attendance in this study 124 children (59%) of Down syndrome children attended school and reflect the current situation in Thailand[7-9,11]. However basic medical and pregnancy screening[4,7] provided to the basic non-medical developmental stimulation support system in Thailand is very variable. The present study also shows that DS children receiving regular early intervention had a statistically higher school attendance record than those who had non-regular early intervention. Results from this present study are an example: partial, special department system are available for Down syndrome children to reach non-medical health and school placement. Down syndrome children who attended the early intervention program can be helped to attain their maximized developed potential. Most of the early intervention programs[13,15,17] are available only in big medical institutes and some provincial hospitals. This may be the reason explain why Down syndrome children particularly those from provincial area, low socioeconomic status, under educated parents are underserved by non-medical services and cannot receive proper early intervention and may thus have lower developmental quotient (DQ) than those receiving early intervention. In the future, public and private organizations should have more concern in supporting these children and their families to reach the basic requirements for better health and full potential in the future.

## Conclusion

A regular early intervention start has been proven to have a positive effect on development. Down syndrome children receiving regular early intervention attained their significant developmental milestones many months earlier than those receiving non-regular intervention in all the developmental domains. The school attendance number of Down syndrome children receiving regular early intervention was significantly higher than Down syndrome children receiving non-regular early intervention. School attendance was correlated with maternal education and attended regular early intervention.

## Potential conflicts of interest

None.

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## ลักษณะทางคลินิกการกระตุ้นพัฒนาการและการเข้าโรงเรียนของเด็กกลุ่มอาการดาวน์ ที่สถาบันสุขภาพเด็กแห่งชาติมหาราชินี

อดิศรสุดา เฟื่องฟู, ขิ่ม สกุลนุ่ม

*กลุ่มอาการดาวน์เป็นสาเหตุของพัฒนาการล่าช้าจากความผิดปกติของโครโมโซมที่พบบ่อย พบความผิดปกติร่วมได้หลายระบบทั้งทางกายและพัฒนาการ*

***วัตถุประสงค์:*** *เพื่อศึกษาลักษณะทางคลินิกของความผิดปกติที่พบร่วมและการกระตุ้นพัฒนาการในเด็กกลุ่มอาการดาวน์ที่เข้ารับการกระตุ้นพัฒนาการที่หน่วยพัฒนาการเด็กสถาบันสุขภาพเด็กแห่งชาติมหาราชินีศึกษาความแตกต่างของพัฒนาการและการเข้าโรงเรียน ของเด็กกลุ่มอาการดาวน์ที่ได้รับการกระตุ้นพัฒนาการอย่างสม่ำเสมอกับเด็กที่ได้รับการกระตุ้นพัฒนาการไม่สม่ำเสมอ ปัจจัยที่มีผลต่อการเข้าโรงเรียนของเด็กกลุ่มอาการดาวน์*

***วัสดุและวิธีการ:*** *เด็กกลุ่มอาการดาวน์ที่เข้าโครงการลงทะเบียนเด็กกลุ่มอาการดาวน์ที่สถาบันสุขภาพเด็กแห่งชาติมหาราชินีในช่วง เดือนมิถุนายน พ.ศ. 2553 ถึง เดือนมกราคม พ.ศ. 2557 จำนวน 285 ราย เด็กกลุ่มอาการดาวน์ ที่ได้รับการกระตุ้นพัฒนาการที่หน่วยพัฒนาการเด็กจำนวน 210 ราย ทำการศึกษาถึงลักษณะทางคลินิกและประเมินพัฒนาการโดยแบบทดสอบ CAT/CLAMS บันทึกอายุที่มีพัฒนาการในด้านต่างๆ ได้แก่ พัฒนาการด้านกล้ามเนื้อมัดใหญ่และเล็กพัฒนาการด้านภาษา พัฒนาการด้านการช่วยเหลือและสังคมและจำนวนการเข้าโรงเรียนของเด็กกลุ่มอาการดาวน์เปรียบเทียบระหว่างเด็กที่ได้รับการกระตุ้นพัฒนาการสม่ำเสมอ กับเด็กกลุ่มอาการดาวน์ที่ได้รับกับการกระตุ้นพัฒนาการไม่สม่ำเสมอและปัจจัยที่มีผลต่อการเข้าโรงเรียนของเด็ก*

***ผลการศึกษา:*** *พบโรคหัวใจพิการแต่กำเนิดเป็นความผิดปกติที่พบร่วมบ่อยที่สุด ส่วนมากผู้ป่วยกลุ่มอาการดาวน์ร้อยละ 84 ได้รับการกระตุ้นพัฒนาการสม่ำเสมอ พัฒนาการของเด็กที่กระตุ้นพัฒนาการสม่ำเสมอกับกลุ่มที่ได้รับการกระตุ้นพัฒนาการไม่สม่ำเสมอพบว่าเด็กกลุ่มแรกมีพัฒนาการที่ดีกว่าอย่างมีนัยสำคัญทางสถิติในทุกๆ ด้าน เช่นเดียวกับการเข้าโรงเรียน*

***สรุป:*** *การกระตุ้นพัฒนาการในเด็กกลุ่มอาการดาวน์อย่างสม่ำเสมอส่งผลดีต่อพัฒนาการและการเข้าโรงเรียนของเด็กกลุ่มอาการดาวน์อย่างมีนัยสำคัญทางสถิติเมื่อเปรียบเทียบกับเด็กกลุ่มอาการดาวน์ที่ได้รับการกระตุ้นพัฒนาการไม่สม่ำเสมอ*