

Family Adjustment and Use of Rehabilitative Services for Children with Down Syndrome Aged 0-5 Years in Petchaburi Province, Thailand

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ABSTRACT

Introduction: This study explored family adjustment and access to rehabilitative services for children with Down syndrome aged 05 years in the ecoculture of Petchaburi Province, Thailand. It fills a need for understanding for early childhood with intellectual disabilities in rural Thailand. **Methods:** The study formed a focus group at Pra Chom Klao Hospital discussing their family guided by family systems genograms with eight (8) participants from five families, followed by home visits. Qualitative data collection including field notes, pictures and discreet video recordings of the group discourse. The analysis used rigorous procedures for constant comparison, analysis of space, content, domains and critical discourse analysis. **Results:** The study found that participating families adjusted to emotional ruptures in the home, health, cultural stigma, economic and educational discrimination. Cultural and religious resources from mother's side of the family contributed most during and after health crisis in the first 2 years of birth. Parents are concerned about seriously delayed development of communication skills in the period 2 ½ to 5 years of age. Participating families discovered their tendency to limit the possibilities for their child's independent living and occupation. **Conclusions:** Recommends further development of family support groups for ID in Petchaburi, language and communication strategies, abuse training for mothers and discussion on reproductive and inheritance rights and exploring sibling relations and economic options. Service provision might consider reduced hospital stigma, advocacy for inclusive public and work based play areas, increased support and professional development for community based counselors and special education center extension services.

Keywords: Down syndrome, Family adaptation, Ecocultural CBR

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1. INTRODUCTION

Down syndrome in Thailand affects 39,406 (Male-20,490, Female-18,915) (NSO/ICT, 2012) persons who mainly (81%) live outside of municipal zones with limited access to disability services. The IHPP (2007) has a moderate occurrence of intellectual disabilities in Petchaburi (0.25 - 0.33 as percent of population) with 411 boys and 459 girls (NEP, 2014) serviced by one child development center, one special education center and Panyanukul School. Only 1 in 4,000 attends inclusive classrooms. Therefore, Petchaburi has a significant number of families adapting and using rehabilitative resources in Petchaburi for children with Down syndrome. Early childhood interventions are the best hope for promoting learning for these children for which there is was no previous study in Thailand.

According to Christodoulou (2015) down syndrome occurs due to an extra copy of chromosome 21. This genetic difference results in limitations to some extent of cognition, short-term memory, articulation, progress in language, and possibly vision and hearing. They have a need for mental - cognitive development regarding encoding and decoding of language, coordination and executive functions. They also may experience health issues such as heart disease, type 2 diabetes and obesity. Their condition results in delayed physical and mental development. Behaviorally, there are emotional outbursts, communication gaps, memory gaps, and persistent issues with personal hygiene, dependency in eating and poor nutrition, movement and micro motor skills development. Down syndrome inhibits a normal learning path for these children compared to children at the same age, so it is in the home where individualized learning and development can occur in partnership with professionals.

It is important to define other key terms. Parents are singles or partners, one of whom has a blood tie to and/or legal custody of a child. Family is understood not as parents and their child with Down syndrome, but more broadly as a kinship group and an emotional unit (Kerr, 2000). Rehabilitation is the effort of a person with impairment or delay in development to adjust and enjoy the best possible quality of life. Rehabilitative resources consist of the broad span of resources outlined in the World Health Organization CBR Matrix (2004) and guidelines (World Health Organization, 2013), including the families themselves, their neighborhoods, PDOs, local GOs and NGOs, experts and practitioners, agencies and

institutions in health, social services, education and more. This human environment surrounding the person with disability can be referred to collectively as the rehabilitative cultural ecology. Culture here is understood anthropologically as the production of human knowledge, behavior and cultural artifacts. (Nihira, Weisner, & Bernheimer, 1994; Magasi, et al., 2015; Arbuckle, 2010) This is discovered through cognitive, behavioral or material symbols understood by participants in a culture. Cultural ecology then is the study of persons, their habitats, symbols, behaviors, artifacts and the meaning they assign to them through families and through their relationship to the wider community. Ecocultural CBR in this study refers to rehabilitation culture and coordinated efforts by families, as they relate to communities and various related services or support structures. It is constituted by the **context** of family opportunities and constraints, family **perspectives** on their lives and circumstances, values and goals and family proactive **efforts** to accommodate the child with developmental delays. (Parmenter, 2001) and holistically promote the child's progress (Magasi, et al., 2015) Prior Thai CBR studies emphasized agency-level cooperation (Cheausuwantavee, Suwansomrid, & Kraisingom, 2015), so exploring how family systems or kinship networks function with young children with Down syndrome is potentially very significant.

In sum, many issues require a family to adapt over time, while they may not have access to resources needed for raising their child with Down syndrome. The problem of early childhood intervention and rehabilitation will therefore be studied in terms of family adjustment and access to rehabilitative services for children with Down syndrome aged 0-5 years in Petchaburi province, Thailand.

Purpose of the study was

1. To understand family adaptation and use of rehabilitative resources for children with Down syndrome ages 0 to 5 years in Petchaburi, Thailand
2. To understand family systems as they interact with the learning and development needs of children with Down syndrome in Petchaburi homes and communities.
3. To understand the range of family cooperation with outside knowledgeable persons or institutional resources that are available to families in Petchaburi to promote community based rehabilitation for children with Down syndrome

The benefits of the study include improved intercultural understanding of Down child development and in relating family needs with service in CBR and promoting knowledge, perspectives, connections and techniques for partnering with these families.

2. METHODOLOGY

The study formed a focus group at Pra Chom Klao Hospital discussing their family guided by family systems genograms with eight (8) participants from five families, followed by home visits. Qualitative data collection included field notes, pictures and discreet video recordings of the group discourse. The analysis used rigorous procedures for constant comparison, analysis of space, content, domains and critical discourse analysis.

2.1 Study Sample

The inclusion criterion was families with children ages 0 to 5 years of age with DS who have used the services of the Center for Child Development, Prachomklao Hospital and reside in Petchaburi. The study placed a participation limit of 10 families. The Pra Chom Klao Hospital offered meeting space and the special education center offered day care. The study identified 8 participants from 5 families of children with Down syndrome aged 0 – 5 in Petchaburi. A 9th parent backed out after the first session due to her home being quite a distance from the hospital and needing income from work. Participants spoke Central Thai but there were 6 mother tongues in the group: Karen, Black Tai, Lao Phuan, Lao Wiang, Lao Issan and Kui. Participants learned how the group was to be conducted and signed consent forms with freedom to terminate at any point.

2.2 Data Collection

The instrument for this study was a family genogram guide with chosen elements for analysis of a family system (Friedman, 1985; Kerr, *One Family's Story: A Primer on Bowen Theory*, 2000; Darrel, 2014; Frame, 2000; Morgaine, 2001; Sheridan, Eagle, & Dowd, 2005) where family is an emotional kinship network across generations and locations. The resulting instrument had supporting questions on the following topics:

1. naming
2. medical history
3. rites of passage
4. rules of proximity & locality
5. frequency patterns & quality of
emotional contact
6. closest/ most distant relation in each
generation
7. sibling position and family constellation
8. relationships & operating principles
9. emotional cutoff
10. ethnicity & ethnic presentation
11. religious affiliation
12. socioeconomic level of each household
13. intense issues

This instrument was discussed and translated into conversational Thai language by Masters students studying group counseling at Ratchasuda College, Mahidol University, Thailand and approved by the IRB for use in a self-directed parent focus group at Pra Chom Klao Hospital, Petchaburi which met 7 times between April 20 and June 30, 2016. In each session, the participants selected an item from the instrument, drew their genogram and presented it to the group for 5 minutes, followed by discussion, all of which was video recorded. Seating arrangements and non-verbal signals, vocabulary and events were recorded in the field journal.

Data was also collected through participant observation in home visits. The lead researcher, a child development nurse, occupational nurse and a special education teacher in Petchaburi observed the focus group and provided interpretations of the transcribed discourse data. Parents volunteered some pictures to us. Spatial maps of home and group seating was done and the child playing in their home environment was observed, including interactions with family and neighbors, guided in part by the search for interaction symbols and developmental stages of play. (Hughes, 1995)

2.3 Data analysis

Domain analysis supplemented the results in each step. The researcher recorded 50 pages of field notes with 127 long entries. Constant comparison of the field notes codified data, developed a registry and generated categories, properties, and hypotheses about the adaptation and resource usage of families of children with Down syndrome aged 0 – 5 years in Petchaburi province. Names of participants were codified in a manner appropriate to local culture salutations, where Mr/Mrs + Child's nickname was the colloquial form. The nickname was further translated into English to disguise the child and family. Therefore there were 8 study participants who were identified in the field note registry with a four digit code broken into first digit (family number), second digit (sibling order of child) and third and fourth digit (primary care giver order), such as Ruby's mom (1101). This continued with four stages of the constant comparative method: (1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimited theory, and (4) writing the theory or recommendations. (Glaser, 2008)

Summary of discourse

The discourse deepened an understanding of 9 categories of adaptation and 5 categories of resource usage of families of children with Down syndrome ages 0 to 5 in Petchaburi Province, Thailand. Resource usage showed a high level of participation in the social security program, hospital (age 02.5) and especially the special education center (age 2 to 5). Other rehabilitative services showed a lack of participation. Finally, the use of critical discourse analysis discerned that environmental and economic developments in Petchaburi have largely left these families behind with few options for obtaining land or resources and with social participation of the child in society s a serious lack of hope or forethought.

Critical Discourse analysis (CDA)

The study identified from 1,647 comments by participants in the sample data 8 factors and 8 sub factors of adaptation and 7 factors and 1 sub factor in resource use for rehabilitation of children with Down syndrome aged 05 in Petchaburi, Thailand. Discourse items related to the following analytical framework that emerged from the generalizations of the field notes data. Sub points were added according to the discourse in the focus group. The total items for each factor for each item is found in Table 1 below.

Table 1 Raw Scores for Metacategories of Discourse

analysis framework		adaptation of families							resource usage						
00	01	12.1	13	14	15	16	17	18	21	22	23	24	25	26	27
Research	Group Process	reality of a DS child birth	economic factors	cultural factors (14.1 stigma 14.2 social acceptance 14.3 cultural practices	health factors	child development 16.1. home 16.2.	Independent Living	sexual life adaptation of parents	provider needs	hospital services	social insurance	education 24.1 structure	environmental resources	external threats to family	future developmental ideas
6	11	161	83	292	126	127	36	77	0	65	1	55	14	1	59

This demonstrates that families of children with Down syndrome ages 0 - 5 years in Petchaburi Province focused particularly on cultural, psycho-religious, child development and health adaptations while the discussion of resource usage by these families tended to talk most about hospital services, the resources for the child's future and education. To promote self-

criticism, the field notes also had insights into the research process and the group process. The literature on CDA (Rear, n.a.; Parker, 1992) is very useful for this kind of study.

3. RESULTS AND DISCUSSIONS

3.1.1 Key findings

Regarding family resilience and adaptation was mediated in the participating family systems to meet the needs of their toddler with Down syndrome. They overcome stigma and issues of care conflicts primarily by creating distance from ancestral homes and avoiding discrimination. There are common adjustments based on acceptance of a new born with Down syndrome, holding down jobs and relationships and pursuing special education. However, the cultural expression of inclusion and forms of adjustment depend very much on the kinship network of the mothers in this study. The families foresee obstacles and lack of choice in educational and only during the focus group did they discover the concept of independent living for their child.

A great resource for child development in this study is the fathers, who are willing to play with their child as in some studies. (Childress, 2011) However, social pressure from neighbors may pull parents off for drinking or talks of a social nature that exclude the child. Finally, sexual abuse children with Down syndrome is deemed by parents a high-level threat to girls and a medium -level threat to boys. This threat comes from kin (supporters) and for others the threat comes from neighbors. Mother's response is to severely limit child independence, self-initiative and development. The children respond often with non-cooperation.

Information from the PWD cards of the children was recorded. The cards data includes the citizen number and PWD registration number of the child and of the designated caregiver. Mothers are the designated caregivers, while fathers tend to be family income earners, with the notable exception of Kiss' father who did not participate in the study and is not a designated caregiver, who nonetheless provided the bulk of daytime care during the first 4 years. What are we seeing in terms of parenting styles, resilience, gaps and untapped resources?

3.1.2 Parenting style

Parents exhibited two of the types of parenting styles: permissive, authoritarian, and authoritative parenting. Permissive parenting style was observed including an indulgent

dimension, like stating extreme punishments to the child and does not actually do them. Authoritarian parents also displayed physical coercion, verbal hostility, and non-reasoning/punitive styles. For example, the parent might yell or shout when the child misbehaves (verbal hostility). Authoritative parenting (through connection, regulation, and autonomy where they explain the consequences of behavior to child and offer the obstinate child a choice) was not observed, but was talked about by two participants.

Monitoring by parents maintains visual contact with the child who plays independently. Of the 8 parents, a father was observed *playing with toys with a child* because the space in their small living room inhibited child movement while entertaining guests. In another case, an older sibling was observed in parental roles with a younger brother with Down syndrome, with mother's supervision and giving directions to the older sister, rather than directly to the child. This pattern is common in Thai families (Issaranurak & Suthisukon, 2007).

Parental closeness was observed as keeping a wide physical distance from each other, modelling gender distinction) and lower / higher eye / head level from the floor depending on age and seniority. None of the families lived with or near their parents so this interaction was only observed in a home where a mother's brother visited.

Family resource usage behaviors were also considered. Rural participants primarily used motorcycles to carry their children to rehabilitative resources located 10 - 30 kilometers away. The satellite centers for the special education centers effectively reduced the travel distance to 3 to 5 kilometers for some of families in the 8 zones covering all of Petchaburi. Most of this travel is done exposed to hot sun, dust, wind and rain along the way. It is not an easy life. Only two of the five families could afford a car of their own, based on businesses or middle-income salaries. These are the only early childhood intervention options for their children

The significance given by parents to the range of various services changed over time. From birth to two years, the field notes had a distribution of services as follows: 1. hospital(s). Although standard treatment used both local health centers, district (secondary) and provincial (tertiary) hospitals, particular emergencies and surgery were handled by hospitals as far as Rachaburi, Bangkok and Hua Hin. Study participants reported weekly visits to the hospital during those two years. 2. Social services. Interestingly, all of the families have registered their

child with disability at the Petchaburi Provincial Office of the Ministry of Social Development and Human Security. They receive disability benefits of 800 baht per month and reimbursement for part of the health costs. However other benefits such as grants or loans were not accessed and the burden of time, travel and loss of income was very difficult for the families with lower socioeconomic status living apart from family.

After about 2 years, however, the child's family's relationship to the hospital subsidies dramatically and in its place is the Petchaburi special education center. The center also operates 8 extension centers staffed by two teachers who travelled from the special education center in Petchaburi. One center was closed temporarily by the story of a ghost. It was noted that social services became a relatively passive relationship. One family reports that their child is ready to transition to an inclusive education environment but only one school administrator will consider the child's admission.

None of the participants have previously experienced other professionals in the area of disability working with them on either adaptation or resource identification and assessment. They tend to rely mainly on peers (fellow parents of children with Down syndrome) to consider options.

4. CONCLUSIONS

The study found that cultural adaptation is occurring among the participating family systems to meet the needs of their infant with Down syndrome, but there are significant gaps in resource usage in Petchaburi.

Families overcome stigma and issues of care conflicts primarily by creating distance from ancestral homes and avoiding discrimination and abuse. There are common adjustments based on acceptance into the home of a new born with Down syndrome and holding down jobs and relationships. However, the cultural expression of inclusion and forms of adjustment depend very much on the kinship network of the mothers in this study. The families foresee obstacles and lack of choice in education and only during the focus group did they discover the concept of independent living for their child.

Siblings in this study appear to be accepting and loving of their older/younger sibling with Down syndrome as play partners. Parental expectations for siblings is not reciprocal as

expected (Issaranurak & Suthisukon, 2007; Jitbrapan, 2014) and mothers have many punitive behaviors that restrict child autonomy primarily by telling the child to do something (keep away, come back, let's go) and in providing praise for compliance primarily by telling the child to do something (keep away, come back, let's go) and in providing praise for compliance.

Rehabilitative resource use by these families focused on temples/monks and hospitals in infancy, which then transfers its focus to the special education center at age 2-3. This is accompanied with greater awareness of other families with similar challenges and greater experience of love and normalcy in the relationship to the child. This however also comes with increased awareness over the ways the child is not keeping up developmentally with other children, causing stress and possibly depression. Disability insurance registration had already been completed for all participants prior to this study through close cooperation and referral between the hospital child development unit and the special education center.

The recommendations deriving from this study are as follows.

The parents of children with Down syndrome in the 3-5 years age group call for development of a reading program for their children. One impediment in the way of the child in developing reading skills is the child's visual impairment. The focus of one or both eyes is not clearly centered. Further innovations should be introduced such as glasses or readers specially designed to facilitate textual recognition, vision focus and cognition for a child's visual impairment. Graded reading materials with child-centered graphics in the mother tongue/s of the child should be encouraged, which may require digital editions with global translators replacing English text with a choice of local languages, not just Thai. The reason that Thai is not made as a formal recommendation is because the outcome of learning of a child in Petchaburi seems to be dependent on the kinship rules and sense of inclusion in local cultures.

Development of rudimentary outdoor play spaces has already occurred naturally for three of the families, one at an advanced level (on the grounds of the company that employs them) and is inadequate for two families. More adequate outdoor play spaces for low income families should be developed, including possibly one at a company and one through cooperation in a fishing village, for example, by possibly converting an old boat or floating platform into a seaside playground with lots of see through spaces. The play spaces should be configured not

merely for physical development of children, but to promote cooperative and role play and communication. A parent support group working with the Provincial offices of the SDHS Ministry might facilitate this.

Reduction of stigma in medical service delivery is recommended. Two examples of stigma were found. First, the district hospital asked the mother not to speak her language to the child, but to focus on Thai language only “to not confuse the child.” A policy of multiculturalism and interpreting staff is encouraged with respect to child development to enhance family adaptation, remove impediments to services for children developing communication / language in a minority language. A second example was a departmental nurse head who felt that the frequent medical use for a child with Down syndrome should have been prevented by better screening and mandatory abortion. The knowledge of the nurse in question (reported by the parent) about Down syndrome in infants was good, as per previous studies (Kor-anantakul, Awapark, Suwanrath, Suntharasaj, & Hanprasertpong, 2013), but the attitude was not informed by the experience of parents of children with Down syndrome at age 5 who thoroughly enjoy their relationship with their child OR with the fact of increased longevity, great progress in promoting independent living and the opportunity for customized employment for persons with developmental disabilities in Thailand.

Medical services in counseling and speech therapy are greatly needed by the parents of this study. However, the educational approach to genetic and crisis counseling in hospitals needs space for multifaceted emotional listening and support groups. Speech therapy lacks sufficient staff hours. Monitoring of needs might improve speech therapy programming and assist in expansion of staff hours in Petchaburi district-level (secondary) hospitals

Social insurance benefits for persons with disabilities have expanded in Thailand; however, the parents of children with Down syndrome in Petchaburi have not become aware of some interesting supports for creating development spaces and for partial state support for parent disability-related support groups in Petchaburi is still largely untapped.

Educational programs in Petchaburi offer no truly inclusive learning environment. A Family systems approach has shown that the educational path for children with Down syndrome has great potential for independent living and future employment through self-employment and kinship networks. These potentials need to be enhanced through a careful study of the parent's

experience of independence and employment, asking what aspects of this their child might be able to do 'like mom and dad.' It appears that many parents view the option of study at Ratchanukul School with doubts over the treatment of the child and possibly the perceived benefit to the child and family.

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