

## BRIEF REPORTS

---

# Stigma, Learning and Inheritance: An Ecocultural Study of Adaptation and Resource use among Families of Children with Down Syndrome in Thailand

Donald S Persons\*

### ABSTRACT

**Purpose:** *This study explored family adjustment and access to rehabilitative services for children with Down syndrome, between 0-5 years of age, in the ecoculture of Petchaburi Province, Thailand.*

**Methods:** *The study used a family systems genogram in focus group sessions at Pra Chom Klao Hospital, and made home visits to the eight participants from five families in Petchaburi Province, Thailand. Qualitative data collection included field notes, pictures and video recordings of the 7 focus group discussions. The analysis used rigorous procedures for constant comparison, analysis of space, content, domains and critical discourse analysis.*

**Results:** *Participating families had adjusted to emotional ruptures at home by moving out. They were resilient in the face of health, culture, economic and educational stress. Cultural and religious resources, especially from the mother's side of the family, contributed most during and after health crises in the first 2 years of childhood. Parents were concerned about seriously delayed development of communication skills when their children were in the 2 ½ - 5 years age group. Parent conviction that the children would be lifelong dependants limited the possibilities for fostering independent living and occupations for these children.*

**Conclusion and Implications:** *This study contributes to family and community-based rehabilitation strategies, stigma reduction and promotion of early childhood intervention for children with Down syndrome in Thailand. It found moderate public stigma, obstacles in educational transitions and resource use, and limited parental understanding of children's inheritance and future quality of life. The recommendations made are: better development of*

---

\* **Corresponding Author:** Lecturer, Department of Rehabilitation, Ratchasuda College, Mahidol University, Thailand.  
Email: donald.per@mahidol.ac.th

*family support groups and rehabilitation counselling services, language and communication strategies, abuse training for mothers, and discussion on inheritance rights which offer insight into sibling relations and employability. Service provision can consider reducing hospital stigma, advocacy for inclusive public and work-based play areas, increased support and professional development for community-based counsellors and special education centre extension services.*

**Key words:** *Down syndrome, family adaptation, ecocultural CBR, Thailand*

## INTRODUCTION

Down syndrome in Thailand affects 39,406 persons (male-20,490, female-18,915) (NSO/ICT, 2012) who mainly (81%) live outside municipal zones with limited access to disability services. The IHPP (2007) shows a moderate occurrence of intellectual disabilities in Petchaburi (0.25 - 0.33% of population), with 411 boys and 459 girls (NEP, 2014) serviced by one child development centre, one special education centre and Panyanukul School. Therefore, Petchaburi has a significant number of families adapting and using rehabilitative resources in the area for children with Down syndrome.

This study is the first exploration of ecocultural CBR in Thailand. Ecocultural CBR, defined as the creation of ecology and culture around the family and person with disability (Nihira et al, 1994), is an integral form of CBR in the CBR Matrix (World Health Organisation, 2004) and guidelines (World Health Organisation, 2013). 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). Thai studies on CBR have focused more on policy and agency-level cooperation (Cheausuwantavee et al, 2015), so exploring how family systems or kinship networks adapt to young children with Down syndrome is potentially very significant.

## METHOD

### Study Sample

In this qualitative study, caregivers from families who had young children with Down syndrome, residing in Petchaburi, were enlisted through public

announcements. The Pra Chom Klao Hospital offered meeting space and the special education centre offered day care. The study identified 8 participants from 5 families of children with Down syndrome aged 0 – 5 years. A 9th parent backed out after the first session because her home was quite a distance from the hospital and she needed to work for a living. The participants signed consent forms.

Interestingly, all the participants spoke Thai but there were 6 mother tongues in the group: Karen, Black Tai, Lao Phuan, Lao Wiang, Lao Issan and Kui.

### **Data Collection**

A genogram instrument discussed 13 areas of family systems and was adapted to Thai from intercultural psychology and family systems theory (Gardiner et al, 1998; Frame, 2000; Kerr, 2000; Wilbur, 2000; Sheridan et al, 2005; Darrel, 2014) for use by a self-directed parent focus group at Pra Chom Klao Hospital, Petchaburi. The focus group met 7 times, between April 20 and June 30, 2016. In each session, the participants presented genogram drawings about their family, and the group discussions were video- recorded. The researchers were observers, along with a child development nurse, an occupational nurse and a special education teacher in Petchaburi to aid in interpretations of discussions and data.

Participants were also observed during home visits.

### **Analysis**

The data was transcribed and analysed using spatial mapping, constant comparison and Critical Discourse Analysis (Parker, 1992) . The following report concerns stigma, learning and inheritance among children with Down syndrome in Petchaburi.

## **RESULTS**

### **Stigma**

Stigma is the operation of stereotypes, feelings of prejudice and discrimination enacted against a member of a minority group in society (Corrigan, 2004). As such it can be categorised in terms of institutional stigma, public stigma and self-stigma (Werner, 2015). Stigma was identified using a lexical analytical model (Goffman, 1963; Kusow, 2016) by first developing a lexis of social differences from

the sample. Public stigmatic lexis from the data was limited to Thai semantic units heard by parents <35 yrs of age, as follows: 'feeble brained,' 'retarded' / bənyə on/ 'weak' /I:piəək/ 'Like this' /yəng əiə/ which caused them discomfort.

Two examples of institutional stigma in medical services were noted. The first was when the district hospital nurse asked the mother not to speak her language to the child, but to focus on Thai language only, lest there was further delayed development. The second was in an encounter with a departmental head nurse who felt that the frequent medical requirements for a child with Down syndrome should have been prevented by better screening and mandatory abortion, indicating prejudice in spite of knowledge (Kor-anantakul et al, 2013). Parents of 5-year-old children with Down syndrome enjoy the relationship they have with their children. These children have potential for longevity, and progress has been made in promoting independent living and providing opportunities for customised employment for persons with disability in Thailand. Institutional stigma was also perceived in educational practices which prohibit admission of children with low IQ. Legal sanctions also prevent these children from driving a car or riding a motorbike, which restricts future mobility.

Public stigma, on the other hand, was observed mainly in preferential treatment (overcompensation by others) and/or taunting (local: 'yaa') during attendance at festivals and at play. One parent described how "next- door neighbours were talking to their children" to play properly because the child with Down syndrome did not know better and must be given special treatment because "it is like this." Another parent stated that at the play area of the department store, another child asked what was wrong with the child with Down syndrome. The other mother said that the child was weak and feeble-brained. The implication was that the child with Down syndrome would not understand how to play with other children and would be unable to respond or react appropriately. Amusement at her child's delayed response enraged the mother of the child with Down syndrome. Cooperative play ended abruptly. It seemed like the young girls working at the play area would not intervene to promote cooperative play either, so the mother never took her child back there, an internalised or self-stigma.

Families had adapted to stigma through naming of their children. The study found three patterns: names were either derived from: 1) first letter phonyms (e.g., Pik, Pak, Pek); 2) were given by an aunt; or, 3) had meaning ==> luck; enhancement of one's fortune. Child-naming is a moment of cultural acceptance and incorporation into the family, accompanied by tying a string around the

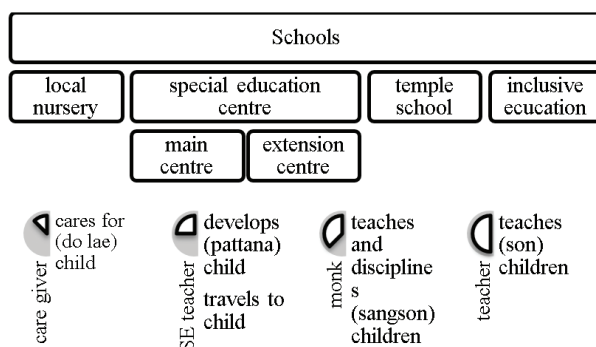
wrist (showing acceptance) or getting the elders and perhaps a monk to bless the child in some form. Cultural activities strengthen family resilience and offer an alternative construction of meaning. Nonetheless, most families excluded their children with Down syndrome during meals with extended family, and in matters regarding where they sit, what they may discuss, and the limit of topics. Four of these families had moved away from ancestral homes to gain greater autonomy after the rupture in formerly significant relationships. In Petchaburi, relatives who worked with the child with Down syndrome included the mother's older sisters and certain brothers. Cultural rules for the father's family varied; some viewed fathers' families as passive, others considered them as equal partners. Kin can enable play and learning.

## Learning

Learning in early childhood care and development in Petchaburi is promoted at the hospital and the special education centre. Parents in this sample viewed education as an opportunity to 'drop off' the child and leave in the care of the school, to enable them to work. Parents did not seem to be fully aware that they should function in a partnership mode with respect to learning and child development through the IFSP (NICHCY, 2014) and IEP frameworks (School & Cooper, 1999; Ministry of Education, 2008; Talbot et al, 2016), a limitation that was found in other Thai studies on education for persons with disabilities (Narot, 2010; Ratchasuda College, 2015).

Figure 1 below is a domain analysis of family interaction with forms of education in Petchaburi. It shows that parents see only four main educational alternatives for their children, and shows corresponding roles of educators and parents.

**Figure 1: Parent Interaction with Educational Services**



These four learning situations have in common the sense of an educational professional being interventionist and parents being passive. The individual needs and progress of the child are reported to parents.

Regarding educational transitions, the special education ends at age 6. One participant took the initiative to discuss with the Aroonpradit [Christian] School the possibility of allowing the brother with mild delay in intellectual development to join his older sister there. The school seems willing to accommodate this when the child is able to communicate. Another family was offered employer funds to transition to mainstream education; however, they had chosen not to, at this point in time, preferring that their boy improve in communication. Parochial and public schools lack personnel trained in special education. It is interesting that parents would pursue parochial schools over the special education-focused Panyanukul School or inclusive public-school alternatives due to their system of discipline and large class sizes (> 50). Petchaburi schools may exclude their child in "inclusive" settings, as was found in Australia (Jackson, 2008). To gain admission to such settings, the child must pass an IQ test administered by psychologists at the main hospital. None had done it. Parental confidence in the ingenuity of their child ("My child is so smart!") made them suspect that IQ testing was more an impediment and social control than a tool for learning.

Parents worry that their children are still unable to make sentences or communicate basic needs at almost 5 years of age. Field observations and toy inventories indicate a lapse in symbolic communication between caregivers and the child between the ages of 3 months - 4 years. Currently, each family invents non-verbal signs as they go along. Home and special education language of instruction and activities such as rote learning of the Thai alphabet are not mutually affirming. Also, formal language acquisition is being significantly delayed by the lack of home-based reading with the child, and perhaps by overdependence on mobile phone applications with low human interaction. Current speech interventions include the clipping and massage of the tongue, and visits to district hospital speech therapists. Play between parents and children was not observed.

How could personalised localised communication be better fostered? One intervention to promote localised communication would be to teach the family to label objects around the house and put up signs with proverbs, especially pictures and signs of warning, information, historical memory and more. Play areas (Hughes, 1995; Down Syndrome Education International, 2015) are needed to promote cooperation, natural exploration and talking. The family might send

the child to playing areas along with other children from that language group, at least for the first two years, so that the mother tongue can be learned prior to Thai language.

Homeschooling learning models might empower parents and siblings to play a role in the child's development. Non-verbal skills and reading with children are teachable methods. By focus group sessions 6 and 7, parents had begun to see the need to coach their child, take their child on outside trips, and create new experiences and new approaches to community play. Their perspectives and initial assumptions had changed during the course of the study. They were now aware of possibilities regarding the future and the potential of their child to become more self-sufficient.

Disability employment interventions such as the Work Ability Index do not seem geared towards persons with intellectual disabilities. The parents were not hopeful that their children could get an inclusive education, live independently or compete for the few jobs available in rural Petchaburi. However, alternatives uncovered by the genogram diagrams opened up real possibilities for local employment by following the path of the parent's route to independence. This helped participants to see limitations more realistically.

### **Inheritance**

Parents who participated in this study had assumed that their child would live lifelong with the mother, perhaps returning to the ancestral home. By the end of the study, participants were aware that the lifespan of children with Down syndrome could extend up to 50 – 70 years. Their child may in fact outlive them. The problem of inheritance is real. This could change their approach towards raising their child with Down syndrome to be independent.

The participants have various cultural inheritance rules characterised by matrilocality, sibling order and gender roles, asset security, sexuality and vulnerability of women, guardianship roles and related requirements. The genograms were critically analysed and the findings on the subject are given below.

Ruby's parents only have this one 4-year-old girl. In principle, whatever they have goes to Ruby. However, they work in a factory and rent a room. They have nothing of their own other than a motorbike. The assets, if any, might be placed in the trusteeship of Ruby's mother's sister.

Cheek's mother is a single parent who lives in a fishing village. She has a house on stilts by the docks. Cheek, a 5-year-old girl, is her only child and has the inheritance right. However, the danger of abuse of a female child/adult with Down syndrome means that it will be difficult to prevent Cheek from being harmed and cheated. Perhaps the mother's relatives who live in the same village will be guarantors.

Eye's parents have some large land holdings on a mountain side which will be of considerable value in future. How can Eye's residence and land use continue to be safeguarded once her parents are gone? The former anarcho-communist village has a history of shared possession, which makes skills in village cooperation very important, with the advantage of mutual assistance by all. The mother prefers Eye to live out her life in this home, and for the older half-sister to take charge of her in the event of the parents' death. She forbids Eye to have an independent life away from home or to have sexual relations as an adult, for fear of abuse.

Noon's parents are doing very well as managers of a large souvenir/food factory, but they are not adding to their ownership of land. Noon's mother's ancestral lands are along the Cambodian border (according to Kui culture) while Noon's dad will not inherit anything because of his Lao culture, which traditionally leaves the home to the youngest daughter. So, when the time comes, the mother plans to move back to divide the land equally among her siblings. There is every likelihood that her siblings will give it all to her. Noon's little sister may get inheritance rights and Noon will become a member of that household or find an independent life with a partner who has inheritance rights. However Noon may have no offspring.

Kiss, a boy, and his sister Kuss are the children of their father's second wife. Since the main wife has no children, these two will inherit whatever is left: major land holdings and houses, cars and motorbikes, and large bank accounts. Kiss' mother assumed that the rule of equal inheritance rights that she turned down in her situation will also be broken, in that she will give the big sister Kuss a greater share of the inheritance and custodianship of her younger brother Kiss. This could be complicated if Kiss develops a profession of his own or if he falls in love, which might cause him to leave home for a time and live independently at a partner's residence. Also, will the constant presence of Kiss create a burden for the mother or the older sister as she seeks to build a family? Can Kiss handle money in the future, just as his mother has handled money through a payday loan business? Mother thinks not. Can he work at the Outlet Department Store



like his mother? Yes, she says. How will he get there every day? She can send him, she offers. Can he manage the upkeep of the house such as the electricity, plumbing, tiles, roof and the like? Possibly...probably, says mother, with the right training and a group of builders working together. Can he drive a car? No. Can he ride a motorbike? No. What if the motorbike were set at a low maximum speed and used only locally? Possibly. He would have to learn how. How about bicycles as transportation? Yes, for sure.

The focus group found that parents had each limited the future of their child. The greatest asset for the children with Down syndrome is the parents' stories about developing their independence. These stories point to an achievable path of child development in Petchaburi.

## **DISCUSSION and CONCLUSION**

The study sought to better understand family adaptation and rehabilitative resource use from the perspective of intercultural family systems. Parents are adapting to stigma through kinship networks as well as in opting to use medical and educational resources. Educational resources were evaluated by parents, and revealed serious access issues and obstacles to transitions out of the special education centre after the age of 6. Participants felt that public schools contribute little to independent living and work development for students with Down syndrome. The continued role of homeschooling needs exploration. The study found that the greatest resource for training the child to achieve a good quality of life comes from the parents' own stories of independence. Finally, the longer lifespan for persons with Down syndrome means that inheritance has become an issue for families; this should make them adopt a more robust approach towards developing their child's abilities. Greater assistance is needed as families of children with Down syndrome in Petchaburi plan for their children and promote cooperation.

### **Limitations**

The study is limited by sample size. Also, the focus is on the parents, rather than on the children. During brief home visits it was not possible to fully catalogue resources in the communities where the families lived. This methodology can only suggest factors in adaptation but not levels, frequency or effectiveness of resources.

## ACKNOWLEDGEMENT

This study was funded by the Ratchasuda College Research Fund, Mahidol University, in the fiscal year 2016.

## REFERENCES

- Allen-Leigh B (2016). Rites of passage for families of children with Down syndrome. (D. Persons, Interviewer)
- Buckley S, Sacks B (2002). Social development for individuals with Down syndrome - An overview. Available from: <http://www.down-syndrome.org/information/development/early/>
- Cheausuwantavee T, Suwansomrid K, Kraisingom C (2015). Meta-analysis and content analysis on researches regarding community based rehabilitation in Thailand and abroad. Proceedings of The 2nd Ratchasuda International Conference on Disability 2015: Beyond ASEAN Boundary for Inclusive Living of Persons with Disabilities. April 21-22, 2015. Miracle Grand Convention Hotel, Bangkok, Thailand.
- Corrigan P (2004). How stigma interferes with mental health care. *American Psychologist*; 59(7): 614–625. Available from: <http://www.academia.cat/files/425-8237-DOCUMENT/Howstigmainterfereswithmentalhealthcare.pdf>. <https://doi.org/10.1037/0003-066X.59.7.614>. PMID:15491256
- Darrel A (2014). Family systems therapy. Available from: <https://prezi.com/gyn4yy-nvwfw/family-systems-therapy/>.
- Down Syndrome Education International (2015). Development and Learning. Available from: <http://www.dseinternational.org/en-gb/about-down-syndrome/development/>
- Frame M (2000). The spiritual genogram in family therapy. *Journal of Marital and Family Therapy*; 26(2): 211-216. <https://doi.org/10.1111/j.1752-0606.2000.tb00290.x>. PMID:10776607
- Gardiner H, Mutter J, Kosmitzki C (1998). *Lives across cultures: Cross-cultural human development*. Needham, MA: Allyn and Bacon.
- Goffman E (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs: Prentice Hall.
- Hughes F (1995). *Children, play and development*. (2 ed.). Boston: Allyn & Bacon.
- IHPP and Health Equity Monitoring Project (2007). Raingan Chabub Somboon Satanakan Khon Pikan Nai Sangkom Thai ©Statistical analysis of the Disability and Infirmary Survey of the National Statistical Office from 2002-2007. Available from: <http://ihppthaigov.net/DB/publication/attachresearch/316/chapter1.pdf>
- Issaranurak S, Suthisukon P (2007). Disciplining your child. *Journal of Health and Development*; 5(1): 105-118. Available from: <http://www.aihd.mahidol.ac.th/sites/default/files/images/new/pdf/journal/janapr2007/9.pdf>
- Jackson R (2008). Queensland parents for people with a disability: Inclusion or segregation for children with an intellectual impairment: What does the research say? Salisbury: Queensland Parents for People with a Disability Inc.

- Kerr M E (2000). One family's story: A primer on Bowen Theory. Available from: <http://www.thebowencenter.org>
- Kor-anantakul O, Awapark P, Suwanrath C, Suntharasaj T, Hanprasertpong T (2013). The knowledge and attitudes of thai obstetrics and gynaecology residents towards down syndrome screening. *Journal of the Medical Association of Thailand*; 96(1): 7-12.
- Kusow A (2016). Stigma. In Stone J., *The Wiley Blackwell Encyclopedia of Race, Ethnicity and Nationalism*. London: Wiley Blackwell: 4778-4779.
- Magasi S, Wong A, Gray DB, Hammel J, Baum C, Wang C, Heinermann A W (2015). Theoretical foundations for the measurement of environmental factors and their impact on participation among people with disabilities. *Archives of Physical Medicine and Rehabilitation*; 96: 569-77. <https://doi.org/10.1016/j.apmr.2014.12.002>. PMID:25813889
- Ministry of Education (2008). *Prarachabanyat Kansuksa Samrap Khon Pikan B.E. 2551. (Special Education Act 2008 A.D.)*. Bangkok: MOE.
- Narot P K (2010). Movement in special education in Thailand. *International Journal of Education*; 33(1): 3-11.
- NEP (2014). *Prarachapanyat Kan Furnfoo Samartaphap Khon Pikan P.S. 2534*. Available from: <http://nep.go.th/th/node/436>
- NICHCY (2014). *Writing The IFSP for Your Child*. Available from: <http://parentcenterhub.or/repository/ifsp>
- Nihira K, Weisner T, Bernheimer L (1994). Ecocultural assessment in families of children with developmental delays: Construct and concurrent validities. *American Journal on Mental Retardation*; 98(5): 551-566.
- NSO/ICT (2012). *2012 Disability survey*. Bangkok: Ministry of Information and Communication Technology.
- Parker I (1992). *Discourse dynamics: Critical analysis for social and individual psychology*. New York: Routledge.
- Parmenter T R (2001). Intellectual disabilities—Quo Vadis? In G. S. Albrecht, *Handbook of disability studies*. London: Sage: 267-296. <https://doi.org/10.1046/j.1365-2788.2001.00344.x>
- Rajanukul Institute (2015). *Down Clinic*. Available from: Rajanukul Institute: [http://rajanukul.go.th/new/index.php?mode=service&group=295&id=4719&date\\_start=&date\\_end=](http://rajanukul.go.th/new/index.php?mode=service&group=295&id=4719&date_start=&date_end=)
- Rachasuda College (2015). *Raingan Chabab Somboon Krongkan Bramun Pol Krongan Judkansuksa Samrap Dek Pikan Doi Krob Krua Laa Chumchon (Krongkan Brap Ban Pen Hong Rien Plian Po Mae Pen Kru. Nakhon Pathom, Thailand: Rachasuda College, Mahidol University*.
- School B, Cooper A (1999). *The IEP primer and the individualized program: Preschool through post-secondary transition. (5th ed.)*. Navato, CA: Academic Therapy.
- Sheridan S, Eagle J, Dowd S (2005). Families as contexts for children's adaptation. In Goldstein, S A. *Resilience in Children*. New York: Springer: 165-180. [https://doi.org/10.1007/0-306-48572-9\\_11](https://doi.org/10.1007/0-306-48572-9_11)

Talbot E, Mayrowetz D, Maggin D, Tozer S (2016). A distributed model of special education leadership for individualized education program teams. *Journal of Special Education Leadership*; 29(1): 1-10.

Werner S (2015). Stigma in the area of intellectual disabilities: examining a conceptual model of public stigma. *American Journal on Intellectual and Developmental Disabilities*; 120(05): 460-475. <https://doi.org/10.1111/jir.12136>, <https://doi.org/10.1111/jir.12207>, <https://doi.org/10.3109/13668250.2015.1010148>, <https://doi.org/10.1352/1944-7558-120.5.460>, PMID:26322392

Wilbur K (2000). A summary of my psychological model (or, Outline of an Integral Psychology). Available from: [http://www.kenwilber.com/Writings/PDF/SummaryofMyPsychologicalModel\\_GENERAL\\_2000\\_NN.pdf](http://www.kenwilber.com/Writings/PDF/SummaryofMyPsychologicalModel_GENERAL_2000_NN.pdf)

World Health Organisation (2004). CBR matrix. Geneva: WHO. Available from: <http://www.who.int/disabilities/cbr/matrix/en/>

World Health Organisation (2013). CBR guidelines (Thai Version). Bangkok: CBM Thailand.