Development of Community-Based Speech Therapy Model: For Children with Cleft Lip/Palate in Northeast Thailand

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Background: *Surgical treatment can reduce disfigurement for children born with cleft lip/palate, however, most children are left with speech and language problems. This creates a new problem as speech and language services is limited.*
Objective: *To combine the principles of Community-Based Rehabilitation (CBR), Primary Health Care (PHC) and institutional medical approaches for reaching and treating speech disordered children with cleft lip and/or palate in remote area.*
Material and Method: *The authors conducted the study from participatory workshops for development of a Community-Based Model.*
Results: *Community-Based Speech Therapy Model for children with cleft lip/ palate was established based on healthcare system.*
Conclusion: *Model can be implemented among children with cleft lip/palate for further process in Northeast and other areas of Thailand as well as developing countries where there is a limitation of speech therapy.*

Keywords: *Community base, Cleft lip/palate, Speech therapy model*

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Cleft lip/palate is one of the most common birth defects, but especially so in developing countries where high risk is associated with deficiencies or poor maternal vitamin and nutritional supplements[1,2,3] or mothers' environmental exposure[4,5]. This situation is prevalent among low socioeconomic status populations. The worldwide incidence of cleft lip/palate is between 0.30 and 2.65/1,000 live births[6]. Cleft lip/palate is indeed a major public health concern in Thailand, where the incidence of cleft lip/palate is between 1.10 and 2.49/1 000 live births[7]. Interestingly, most of the affected persons live in the Northeast, where the annual occurrence of cleft lip/palate is about 745 live births each year[6].

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A cleft lip is generally repaired between 4 and 12 weeks of age, while a cleft palate is done between 6 and 15 months of age[8]. Indeed, surgical repair of clefts resulted in a significant reduction in the social stigma associated with cleft. However, delayed speech and language development with speech disorders are common[9,10,11]. The frequency and severity of speech disorders depend on how late surgical repair was performed, and the degree to which early speech and language stimulation was lacking. This occurs often in developing countries where accessibility to surgical services and speech therapy are poor.

Recently, surgical care including mobile units from non-profit organizations, such as the Association of Plastic and Reconstructive Surgeons of Thailand (APRST), Duangkaew's Foundation, the Thai Red Cross Council, and the Project of the Royal College of Surgeons of Thailand, Thai-American Plastic Surgery

and the American Cleft Palate Associations (ACPA), were sent to remote areas and has brought relief for individuals with cleft lip/palate[6]. These teams primarily addressed surgical issues with little attention to an interdisciplinary approach to cleft care[12]. Speech and language therapy remains a critical requirement considering that the majority of patients are well past the age when speech is acquired and perfected. Unfortunately, most children with cleft lip/palate in Thailand, particularly those who live in the Northeast, receive delayed speech therapy (or none at all) because of a shortage of qualified speech-language pathologists. Nowadays, in a country of 63 million people, there are only 40 speech pathologists. Most of them work in Bangkok, except for 5 in the North, 4 in the South and 1 in the Northeast (where one-third of the whole population lives)[13]. Reasons that relate to inadequacy of trained staff include:

1) Lack of awareness of the magnitude of problems caused by speech and language disorders;

2) Inadequate multidisciplinary hospital that contain qualified speech pathologists and rehabilitation teams;

3) Lack of progression, encouragement, position, instrument and referral system. Government has not recognize the magnitude of the problem. There is little motivation to be a future speech-language pathologists[14]. Some speech pathologists even changed their career after graduation.

The National Sirinthorn Center for the Rehabilitation of the Medically Disabled, who initiated a public role for the rehabilitation of handicapped persons in 1991, and The Thai Speech and Hearing Association, established in 1999, have worked to encourage the government to recognize the seriousness of speech and language disorders. They have facilitated the establishment of new training programs, as well to support the role of the speech language pathologists in forming multidisciplinary, hospital rehabilitation teams.

Notwithstanding the current lack of speech pathologists in Thailand, particularly in the Northeast, and in other developing areas in Asia (*e.g.* Vietnam, Indonesia, India, Laos People Democratic Republic or Laos PDR, Burma, and China) poses a serious problem[15-18].

It is necessary, therefore, to train local healthcare workers for providing intensive and continuing speech therapy. Landis[15] demonstrated that it was possible to train paraprofessionals to provide basic remedial speech services to individuals with cleft palate in developing countries. The philosophy today is to promote the development of healthcare within the community, to share knowledge and skills and generally seek to develop and strengthen the community's capacity to care for itself.

According to WHO/UNICEF[20], we have to pay attention to obstacles in the implementation of CBR and PHC. McKenzie also suggested the problem solving should focus on issues as follow: 1) Inadequate infrastructure and poverty; 2) Training; 3) Community; 4) The balance between hospital and community[21]. Training institutional staff should take into consideration the needs of the community, resulting in a more locally sensitive model. Such a model should also assess the need to develop training programs for trainers based on shared attitudes, mutual awareness between institutions and communities, and prescriptive activity-based training[22].

Wirz[23] argued that a more effective model of service delivery was achieved through a truly CBR approach which reached more children over the long-term, at a lower cost (being in their own community) by trained volunteers or personnel at the primary level. Successful projects in Bangladesh[23], South Vietnam[15,16] and Sri Lanka[24,25] suggested that prior training in disability issues might enhance the effectiveness of subsequent training in communication disorders. Therefore, the authors planned to generate guidelines for helping to train and/or empower local healthcare providers in communities in public education to establish early speech stimulation for these children.

The purpose of the present paper was to set forth a Community - Based Model for Speech Disorders for Children with Cleft lip/palate in the Northeast. This was done by combining of the principle of community-based rehabilitation (CBR), Primary Health Care (PHC) and institutional medical approaches whereupon the authors developed a CBR Model for reaching and treating speech.

Material and Method

The Khon Kaen University Cleft Palate Craniofacial Center, the only interdisciplinary team for cleft lip/palate in Northeast Thailand, invited the Thai Speech and Hearing Association to discuss the problem of speech therapy for patients with cleft lip and palate in September 2003. Process of establishing a Community-Based Model for Speech Disorders for Children with Cleft Lip/palate was divided into three participatory action stages as follows:

Stage I: Consensus from institutional medical or professional approaches

A consensus meeting on Community-Based Speech Therapy Model for Children with Cleft Lip/ Palate, as part of the First Thai International Congress on Interdisciplinary Care for Cleft Lip/Palate 2003, December 1-4, 2003.

Stage II: Consensus from Primary Health Care

A consensus meeting on Development of Interdisciplinary Teams, Networking and Holistic Care in Quality of Life, Health Promotion, Speech and Language Intervention for Thai Cleft Lip/ Palate, in Community, June 3-4, 2004.

Stage III: Model implementation

Stage I: Consensus from institutional medical or professional approaches

Consensus meeting on Community-Based Speech Therapy Model for Children with Cleft Lip/ Palate**:** We conducted workshop which provided knowledge of speech and language management for children with cleft lip and palate by both international and local speakers. Then, the authors divided attendants of The First Thai International Congress on Interdisciplinary Care for Cleft Lip/Palate 2003 to participate in small groups. The panel discussion was on "How to help a professional developed Community-Based Speech Therapy Model for Children with Cleft Lip/Palate based on three levels or units of the healthcare system to provide speech therapy for children with cleft lip/palate in developing countries". The panelists included 23 speech pathologists (1 from Sri Lanka, 1 from Singapore, 21 from Thailand); 2 dentists (Thailand); 2 doctors (1 plastic surgeon from Sri Lanka, 1 general practitioner from Thailand), 2 nurse speech assistants (Thailand), 4 nurses (2 from Laos PDR, 2 from Pakistan), and a special educator (Thailand).

The panelists were assigned for critical discussions of the three levels of healthcare units (*i.e.* strengths, weaknesses, goals and means of generating parameters) and how to formulate a CBR Model for Speech Disorders for Children with Cleft Lip/Palate in Developing Countries. The definition of the three levels of healthcare was as follows:

1. Primary or Community Healthcare Unit included healthcare providers, leaders of the community, parents of cleft lip and/or palate children;

2. Secondary Healthcare Unit or District Hospital included nurses, healthcare providers and paraprofessionals;

3. Tertiary Healthcare Unit or Provincial Hospital included nurses, healthcare providers, and paraprofessionals.

Each group of panelists was provided facilitators who had expertise in speech therapy for cleft lip/palate: Group 1 - the Primary Healthcare Unit: Benjamas Prathanee (Thailand) and Tara Whitehill (Hong Kong); Group 2 - the Secondary Healthcare Unit: Sumalee Dechongkit (Thailand) and Claudia Yun (Taiwan); Group 3 - Tertiary Unit: Sriwimon Manochiopinig (Thailand) and Allison Purcell (Australia).

Stage II: Consensus from Primary Health Care

The Development of Interdisciplinary Teams, Networking and Holistic Care in Quality of Life, Health Promotion for Thai Cleft Lip/ Palate, Speech and Language Intervention in Community: In the second step, the authors invited paraprofessionals and non-professionals from the network of the Khon Kaen University Cleft palate and Craniofacial Center from three provinces in Northeast, Thailand (Loei, Khon Kaen and Bureeram) which were areas where most affected children lived. One hundred and five attendants included nurses healthcare providers from Primary, Secondary and Tertiary Healthcare Units, community leaders, teachers, parents of children with cleft lip/palate, and chair of the Northeastern Cleft Lip/Palate Parents Club (created at the workshop May of 11-13, 2003). There were panelists for a workshop entitled "The Development of Interdisciplinary Teams, Networking and Holistic Care in Quality of Life, Health Promotion for Thai Cleft Lip/ Palate, Speech and Language Intervention in the Community".

The workshop provided basic knowledge, standard protocol of cleft lip and palate management from an interdisciplinary team, Khon Kaen University Cleft Palate and Craniofacial Center as well as case demonstration from professional and parental experiences to establish background in cleft lip/palate. Then, participants were divided into small groups for discussion and brainstorming on topic "What is the problem-solving approach for children with cleft lip/ palate in northeast Thailand?" for development of a network, and a proposal for encouraging the establishment of holistic care, speech and language intervention in a community or local healthcare unit. They were randomly assigned to five groups. Four small groups were formed for a development project to promote and develop healthcare for cleft lip/palate children. The other group discussed the development of an interdisciplinary team, system, and network for holistic care regarding quality of life and health promotion for Thai cleft lip/palate, speech and language interventions in a

community. Each group comprised of multidisciplinary who were representatives from every level of the healthcare system.

Stage III: Model implementation

Hands-on workshop on Speech and Language Management for Cleft Lip/Palate and Development Paraprofessional Manual was conducted in August 2005. The authors invited 8 speech-language pathologists (one of them is a representative from the Thai Speech and Hearing Association) who were interested in community cleft care in Thailand to have a consensus meeting on paraprofessional manuals for training to be a trainer.

This meeting provided hands on workshop on intensive care for speech and language management for cleft lip and palate by international and local speakers. Then, the participants had brainstorming on paraprofessional manual for training to be the trainers in speech and language management in community health care units.

Results

From consensus meeting of institutional, medical or professional approaches *(Stage I)*, the unstructured multidisciplinary group discussions generated procedures for establishing a CBR Model for Speech Disordered Children with Cleft Lip/Palate as show in Table 1. Strength and weakness of each healthcare unit were taken into consideration. Then, the objectives and the outlines on how to solve problems encountered by speech-disordered children were summarized for professional and paraprofessional. *Stage II*, group discussion dealt with issues involving holistic care, speech and language stimulation, and problem solving. Panelists agreed on the basic problems confronting healthcare for speech disordered children as follow:

1) Lack of knowledge and coordination: People did not understand or realize the magnitude of the short- and long-term problems. For example, how to take care of infant feeding, grappling with society

Table 1. Procedure for CBR model for speech disordered children with cleft lip/palate in developing countries

Procedure	Primary healthcare unit	Secondary healthcare unit	Tertiary healthcare unit
Strength Analysis	Three levels of healthcare centers Speech and Hearing Association	Informal network Incipient education cleft palate approach	Multidisciplinary team in some centers Starting a support network
WeaknessAnalysis	Not well organized referral system No support system No basic knowledge	Lack of team work Lack of knowledge Lack of man, power, money management	Lack of experienced in specialists Finances limit networking
Goal	Develop knowledge for local providers in: - overview information - early problem awareness and intervention	Develop a protocol for secondary healthcare provider Guidelines for therapy Early detection and intervention	Encourage government policy Provide experience and knowledge for speech pathology in a multi-disciplinary team
Solutions	Brochures/leaflets Screening form Communication media (newspaper, radio, television) Workshop: overview of information, early problem resolution Awareness and intervention by local staff, paraprofessionals, parents of cleft children, community leaders Network supporting	Workshop: basic knowledge & guidelines for early treatment for secondary healthcare providers Network support	Research & advertisement to encourage government policy Seek financial aid to develop experience & knowledge for speech pathologists Network support

reactions, getting service from the healthcare system, and speech and language stimulation.

2) Low socioeconomic status: Most cleft lip/palate families are poor and cannot afford treatment, not even transportation, accommodation, living expenses, etc. when they are granted an appointment even though they feel the cleft lip/palate child is stigmatized by both family and society. In addition, long term treatment and/or many surgeries for children led to the development of various phobias.

3) Communication disorders and dental abnormalities: Sometimes, families recognized the problems, but could not find any form of speech therapy and dental care at any level of the healthcare system.

4) Local service and referral: Healthcare units or local hospitals cannot serve cleft lip/palate children because of lack of plastic surgeons, speech pathologists, orthodontists, specialist nurses and audiologists. Moreover, no effective referral system or network is in place to coordinate complicated services.

Notably, all group discussions generated the same type of early stage project and problem - solving relative to "Healthcare promotion and development of holistic care, speech and language stimulation for cleft lip/palate". Panelists in the community and healthcare providers in the network created the project shown in Table 2. They proposed projects for promotion and development networking for healthcare providers in cleft care.

Panelists also established a network system for Community-Based Speech Therapy Model: For Children with Cleft Lip/Palate in Northeast Thailand for support the problem-solving project described above, network system is shown as Fig. 1. The network system comprised of functions of each healthcare unit (from community to Khon Kaen University Cleft Palate and Craniofacial Center, Khon Kaen University). Community functions focuses on early growth development and prevention of problems by local people such as community leader or parents. Primary healthcare providers promote global growth development, assessment, and follow up. For secondary healthcare unit provides early abnormality detection and intervention for cleft care and speech therapy as well as referral

Table 2. Healthcare promotion and development of holistic care, Speech and languagestimulation for cleft lip/palate children

Objective	Attendance	Procedure	Place/time	Budget	Responsibility
1) Provide basic knowledge of problems of healthcare for cleft lip/palate children	1) Healthcare providers in every level of healthcare units	1) Workshop for healthcare providers for early interdisciplinary team services in all healthcare unit level	- Hospital	- Khon Kaen University Cleft Palate and Craniofacial Center - Thai Health Promotion Foundation - Local administration - Overseas organizations	Coordination among healthcare providers in a network of community leaders, teachers public relations local people, etc.
2) Promote cooperation of the community and healthcare unit to establish shared responsibility in cleft lip/palate	2) Community representatives - Teachers - Leaders - Parents - Local administrator - Health volunteers	2) Parental share experience 3) Workshop for people and health care volunteers in community and for speech and language service in a local hospital and community	- Community - Community - Healthcare unit		
3) Provide a network for interdisciplinary team in the community		4) Follow-up and assessment in the short term and the long term by an interdisciplinary team	- Hospital - Healthcare unit - Community		
			- During - 2004-2005		

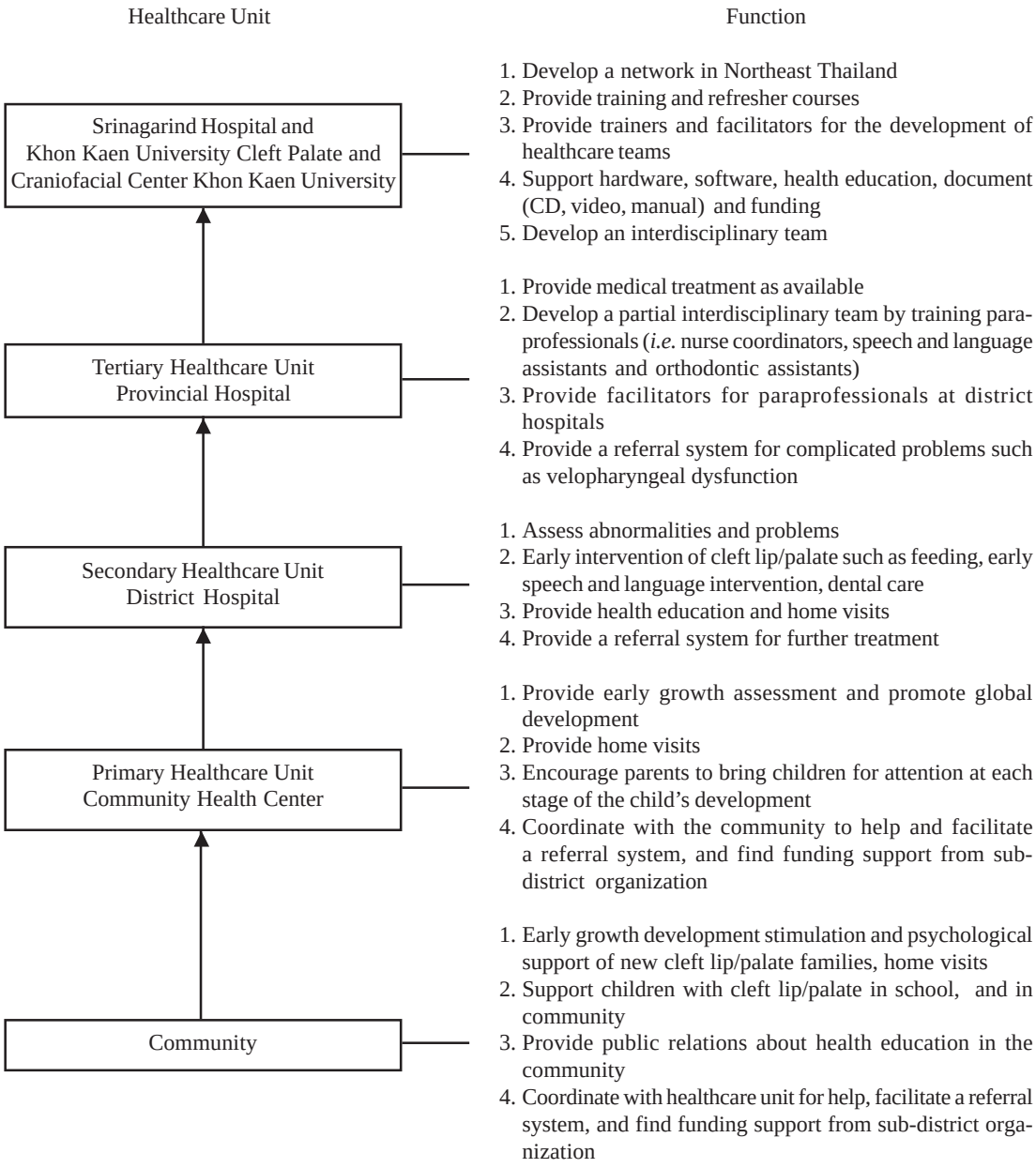

Fig. 1 Diagram of network system for holistic care in quality of life health promotion, and speech and language stimulation for Thai cleft lip/palate children in a community

system. Tertiary health care unit develops a partial interdisciplinary team by training paraprofessional and taking role as caregivers for paraprofessional in lower healthcare unit. Khon Kaen University Cleft Palate and Craniofacial Center is the healthcare unit that develops interdisciplinary team, network system and provides training course for education support and referral system in every healthcare unit level.

For the third stage: Early implement, the first draft of paraprofessional manuals for training to be the trainer was established by speech pathologists that interest in cleft lip/palate. It will be revised for the most benefit for the further process of development "Community-Based Speech Therapy Model: For Children with Cleft Lip/palate in Northeast Thailand". This draft will be designed to benefit further development.

Discussion

According to limitation of speech services for children with cleft lip/palate, constructing a more sensitive holistic model to examine the need for developing a training program for trainers based on shared attitudes, a mutual awareness between institutions and communities, and prescriptive, activity-based training should be done[21,23]. The strategies of development of the model were emphasized on a few reasons that resulted in delayed speech therapy[19] as follow:

1) Many families of affected children have misconceptions regarding both the cause of the impairment and the availability of treatment. Some believe that surgery is the only and final solution and are not aware of supplementary services either that they are required or available. They needed and expected to have more knowledge about cleft care.

2) Most patients live in remote areas or small communities where speech services are not available. In addition, they neither afford nor are unable to travel to receive a treatment in center.

3) There has been a little emphasis on a CBR - approach to the management of speech disorders in children with cleft lip/palate.

4) Healthcare providers or paraprofessionals have little knowledge regarding speech pathology services that are available for individuals with cleft palate.

For these reasons, Community-Based Speech Therapy Model: For Children with Cleft Lip/Palate in Northeast Thailand was established by emphasis on involvement of institutions, community needs, and the principles of CBR and PHC. The key to successful implementation of speech and language therapy training in developing countries is not merely to install correct medical skills, but to maximize both the medical and non-medical benefits of the program. These strategies were conducted for the empowerment of local healthcare providers for increasing the availability of speech therapy for children with cleft lip/palate in Thailand.

Even though the model of service that developed might not meet the needs of the population in every country[18] because development strategies are focused on the most needs of a population in a particular area, it can be implemented in other areas in Thailand and in other developing countries where speech and language services are limited.

Conclusion

Communication impairments limit an individual's social and educational opportunities. This is a typical experience whenever a person with cleft lip/palate tries to communicate with others who are unfamiliar listeners. The speech and language impairments are often associated with an unrepaired, incompletely repaired, or late repaired cleft palate which could range from significant to severe. Some post-cleft repaired children still have language delay and speech disorders[10,11], so speech therapy is necessary.

The authors established a Community-Based Speech Therapy Model: For Children with Cleft lip/palate in Northeast Thailand based on CBR and PHC to remedy delayed speech therapy. This is needed because of a shortage of qualified speech-language pathologists. The further plan is to apply this model and improve the availability of services for the Northeast region and perhaps it can be applied to other regions in Thailand.

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การพัฒนารูปแบบในการให้บริการด้านการฝึกพูดเด็กปากแหว่งเพดานโหว่ในชุมชนภาคตะวันออกเฉียงเหนือของประเทศไทย

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ความสำคัญของปัญหา: *การผ่าตัดเป็นการแก้ไขความพิการของปากและใบหน้าในเด็กปากแหว่งและเพดานโหว่ แต่เด็กส่วนใหญ่ยังมีปัญหาทางภาษาและการพูดอยู่ในขณะที่การให้บริการด้านนี้มีอยู่อย่างจำกัด*

วัตถุประสงค์: *เพื่อพัฒนารูปแบบการฝึกพูดเด็กปากแหว่งเพดานโหว่ในชุมชนที่ห่างไกลจากหลักของการฟื้นฟูสุขภาพในชุมชน ศูนย์สาธารณสุขมูลฐานและการบริการระดับวิชาชีพ*

วัสดุและวิธีการ: *การจัดสัมมนาเชิงปฏิบัติการแบบมีส่วนร่วมของผู้เกี่ยวข้อง*

ผลการศึกษา: *การสัมมนาทำให้ได้รูปแบบของการบริการฝึกพูดเด็กปากแหว่งเพดานโหว่ในชุมชนที่ห่างไกลบนพื้นฐานของระบบสาธารณสุข*

สรุป: *รูปแบบที่ได้สามารถใช้ในภาคตะวันออกเฉียงเหนือ พื้นที่อื่นๆของประเทศไทย และประยุกต์ใช้ได้ประเทศอื่นที่ขาดแคลนนักแก้ไขการพูด*