Action research in home-based early intervention of developmental disorder children

(overview essay)

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Abstract: *This article mainly reports the action research in the home-based early intervention implemented on 20 developmental disorder children aged 0–6 years in Chongqing downtown, which lasted 4 years and aimed at the exploration of the service mode and the transdisciplinary team cooperation mode of the home-based early intervention implemented on the developmental disorder children aged 0–6 years in Chongqing downtown. All team members (professionals and family members) worked together to develop the individualized family service plan (IFSP). A variety of methods was used to record and share personal reflections, observations and assessment, formally and informally, within the team. The result shows that the home-based early intervention service mode has active influence on the children and their families, but the professional integration of transdisciplinary team cooperation mode is much difficult, affecting the results of early intervention.*

Key words: *developmental disorder children; home-based; transdisciplinary team cooperation; early intervention; action research*

1 Introduction

According to "sampling survey on the disorder children aged 0–6 years in China, 2001", China has about 1.417 million disorder children, the number of which is increased at a rate of 0.199 million per year. Among them, the disorder children needing rehabilitation training or service account for 68–75 %, while those accepted rehabilitation training or service account for only 10.46 %, indicating that most disorder children that need rehabilitation training or service are up-brought at home. In Chongqing Municipality, the monitoring data of birth defects based on popula-

tion conducted from October 1, 2008 to September 30, 2011 shows that there were 166 cases of birth defect among 22,250 perinatal infants, with the total incidence rate being 0.007461 %, or 0.0097 % and 0.00692 % in town and village respectively. (Chunyan He, Gaodong Zhang, et al, Chongqing Medicine, 2012). It can be seen that there are many developmental disorder children, but there are not enough organizations that can provide early intervention services in Chongqing, with a large gap existing between the supply and demand. At present, the early intervention modes against developmental disorder children in Mainland China mainly include family mode, center mode and family-center mixed mode. A part of developmental disorder children, after diagnosis in hospitals, rarely accept professional rehabilitation and education training apart from single medical treatment. A part of parents of developmental disorder children try to find early intervention resources for their children, but are always in the absence of professional guidance or unable to find suitable resources, or the existing resources are not well integrated and have not played their maximum efficacy, finally resulting in part of children missing the critical period of early intervention and affecting the development of children potency. Based on the status of early intervention of developmental disorder children in Chongqing Municipality and in reference to some advanced experiences, several senior teachers engaged in early intervention mode in Chongqing have taken the lead in exploring the home-based early intervention mode, and this action research has lasted 4 years and 20 children and their families have benefited therefrom.

In this research, home service teachers directly visited the family of developmental disorder children, giving guidance to the patents how to bring up their children and transferred their rehabilitation training technology to the parents or the main caretakers of children, so as to strengthen the bringing-up knowledge and skill of parents and assist family members to understand the growth and requirements of their children. In addition, the teachers also delivered personal lectures and organized group interactive activities and parent growth group activities to help parents find professional resources and integrate relevant resources. In the provision of children oriented treatment and special education services, parents are the main decision makers and participants and the key of services is the transfer of early intervention technology to the parents or the main caretakers of children and the provision of support to the parents, so that the children can gain the maximum development through early intervention and the families can improve their capacities.

2 Methodology

2.1 Object

The objects of this research are 20 developmental disorder children aged 0–6 years and their parents (or the main caretakers: parents, grandparents or nursemaids). Among them, 16 are boys and 4 are girls, including 3 children with fragile X syndrome, 6 children with developmental delay, 3 children with infantile autism, 3 children with Down's syndrome and 5 children with cerebral palsy. The relevant specialized persons participated in the research are 3 teachers engaged in special education as well as a pediatrician, a physical therapist, a speech therapist and a psychological consultant.

2.2 Action research procedure

2.2.1 Planning: collection of relevant research and practice information in the early intervention of developmental disorder children, understanding the development situation of early intervention in many aspects from background, theoretical basis and service mode to implementation achievements. Drawing up a set of home-based early intervention service procedure with reference to the advanced experiences and in combination with the native actual ecological and existing resources: **Acceptance – assessment – holding individualized family service meeting – drafting an individualized family service plan (IFSP) – executing the individualized family service plan (IFSP) – service assessment – continuous service or referral/settlement – individual track and follow-up visit.**

2.2.2 Action research cycle: operating as the drafted home-based early intervention service procedure, serving successively 20 developmental disorder children and their families, 4 months as a cycle, with the execution time of each individual family service plan being 3 months and the visiting teacher providing visiting service once a week and 1.5 hours at a time. The teachers performed one-to-one teaching or rehabilitation training to the children, made assessment and recommendation on the behaviors of children in family environment, exchanged teaching strategies with parents, adjusted and designed some family activities according to family situation and directed parents how to continue teaching in family environment. In the course of implementation, individual assessment record, family interview record and visiting service log were completed. The implementation procedure of home-based early intervention was assessed every 6 months to understand the execution of the service procedure, highlighting the assessment of the execution of individualized family service plan, the change of abilities of children and their families and the transdisciplinary team cooperation between relevant professionals. Continuous summarization in connec-

tion with individual case researches: assessment, comprehensive study and judge, drafting and implementing the actual experiences in various aspects including IFSP, adjusting and perfecting the home-based early intervention service procedure.

2.2.3 Assessment: Home-based assessment was adopted in this research with children and their families as objects, aimed at understanding the requirements of developmental disorder children and their families, the capacities, resources and study environment of children, the relation and interaction between children and their main care takers. The procedure of measurement is a continuous systematic procedure of disciplinary team cooperation. Children assessment: Curriculum-based assessment was adopted by selecting Portage early education instruction manual of Wisconsin, US as reference to understand the ability level of children in every development fields of daily life, action, language, social behavior and cognition. In addition, environment and ecological assessment was performed through self-compiled "environmental analysis sheet" and "environment adjustment card". In the assessment of children study characteristics, "Neuropsychological development diagnosis scale of children aged 0 to 4 years" and "Denver development screening scale (DDST)" were used to understand the development level of children and "Children's temperament assessment sheet" was selected to understand the temperament level of children. Family assessment: The characteristics and requirements of families were understood through family visit, family interest survey, family environment assessment and parent characteristics survey.

3 Results

3.1 Influence of home-based early invention to the children: As seen from the arrangement at present of developmental disorder children who accepted to visiting service, among 20 cases, through home-based early intervention service for 2–6 cycles, 55 % of the children was successfully referred, 20 % was enrolled into common kindergartens or primary schools, 35 % was enrolled into special education institutions and 20 % of the children and their families continuously selected visiting services. Compared with the children in the same age group who have not accepted home-based early intervention, the rate of entering into kindergartens and common primary schools as well as the routine study, life and basic learning ability is high.

3.2 Influence of home-based intervention on families: 75 % of the families were satisfactory with the home-based early intervention service mode. The upbringing capacity of families, including upbringing style and skill, problem-solving ability and behavior management ability, was lifted for 25 % in average, and the understanding, acceptance, adaptability and consciousness of right were also improved.

3.3 The cooperation between the staff of transdisciplinary team in the early intervention is much difficult, mainly manifested in lack of relevant professional persons and not easy to adjust the time to discuss individual cases, especially for pediatricians and therapeutists.

4 Discussion

4.1 Procedure of home-based early intervention

4.1.1 Detection and referral period: the method of early detection of children with developmental disorder is complete. More and more disabled children can be discovered by antenatal examination, neonatal screening, children protection, children neuropsychological diagnosis and other measures; however, as to the publicity method of the early intervention, the three systems, medical treatment, education and disabled federation which operate independently has led to insufficient knowledge of the meanings, service content and effect at a large number of parents. After the early detection of children with developmental disorder, some organizations didn't know that there are relevant institutions to which the developmentally disabled children can be transferred to or didn't intend to transfer because there was a limited number of organizations which can provide early intervention.

4.1.2 Assessment period: Because the three organizations, i. e. medical treatment, education and disability federation, which are mainly in service of developmentally disabled children, have been in operation independently according to different system and service mode with different assessment methods, a child often needs to receive many assessments and many assessment reports from different organizations, some of which are not very helpful to the follow-up early intervention with woefully inadequate interaction between professions.

4.1.3 Placement and intervention period: Due to insufficient resources, some developmentally disabled children usually choose to go to hospital, early special educational institutions or disability federation rehabilitation center to take the simple drug therapy, early special education or rehabilitation training, or take many early intervention services in many institutions tiredly.

4.2 Home-based Assessment

Home-based assessment includes both children and families. Different families have different requirements of early intervention, professional needs, service needs, information needs, spiritual needs and economic needs, in order of proportion of the

number of people who require early intervention. Families hope early intervention focuses on the needs of children. It is when professionals demonstrate their strength in early intervention service, improve children's ability and gradually build trust in family members that parents reveal the needs of theirs and the family's.

4.3 Drafting and implementation of Individualized Family Service Plan (IFSP)

As the questionnaire survey and the in-depth interview show, families hope that early intervention focuses on children, which is also the reason they take part in early intervention. According to the analysis of IFSP, about 80 % are targeted at children. It is the hope of families that services will be centered on children and the chief approach is home-based early intervention to meet the needs of children.

4.4 Cooperation between relevant professional teams

Many departments like hygiene, population and family planning, civil administration, education, labor and social security and disability federation, etc. are involved in early intervention. The barriers between different departments and regions and the overlapping business operations lead to the incompleteness of the work system of early intervention and planning and coordination work mechanism. The main factor that influences the cooperation between professional teams is the mutual support between professions, professionals, institution resources and institutional sectionalism: all institutions are holding affirmative attitudes towards the integration service of professional teams, but the dilemma to build trans-disciplinary integration teams lies mainly in the shortage of human and institutional resources. At present, the three large systems, i. e. medical treatment, education and disability federation in Chongqing, are carrying on early intervention service and have developed their service mode. However, due to the different professional background, the emphasis, the intervention modes and content are quite different, which results in the selection of a child among several institutions, such as Ningning, a child with cerebral palsy with epilepsy and intellectual disability, who needs to go to the hospital to take regular outpatient services, medicine to control epilepsy, acupuncture, massage to relieve muscle tension; and an-hour cognitive training in a special educational organization, an-hour physiotherapeutic in a disability rehabilitation center and more than three hours on transportation every day.

4.5 Situation analysis (SWOT)

4.5.1 Strengths

- The complete maternal and child hygiene system enables the early screening and the early intervention of children with developmental disorder.
- Parents have a high acceptability of early intervention; they actively take part in the plan and have played an important role.

4.5.2 Weakness

- There is a lack of source of law and policy guarantee in the early intervention of children with developmental disorder, such as the emergency rehabilitation program specific to the poor disabled children of 0–6 years old co-launched by China Disabled Persons' Federation and Ministry of Finance, which is a periodical program, whose service mode is short of system guarantee.
- The insufficient publicity of early intervention and insufficient knowledge of parents often lead to the missing of relevant resources and best service opportunities.
- There is a short supply and uneven distribution of early intervention resources, failing to ensure the fairness and principle of proximity of resource utilization, which has made many children with developmental disorder unable to receive timely service. There is a large gap between supply and demand.
- Although early intervention is a kind of service of humanization, multi-profession, trans-disciplinary team cooperation, the coordination of the trans-disciplinary work is not easy. Parents and children still need to run here and there, tiredly.

4.5.3 Opportunity

- Our country and all levels of government have gradually paid attention to early intervention, and China Disabled Persons' Federation has put forward that "Rehabilitation services will be available for everyone in 2015" and launched emergency rehabilitation program specific to the poor disabled children of 0–6 years old.
- A lot of state-run special schools of the compulsory education stage and civilian-run special educational institutions have begun early intervention service to respond to the requirements.

4.5.4 Threat

- At present, the early intervention work system has not been completed, planning and coordination work system has not been established, and there is no standard service process of the early detection, early diagnosis and early intervention for developmentally disabled children, or a lack of effective connection between working links, which will cause the delay of the best opportunity of early intervention.

- The lack of cooperation between all relevant profession services and institutional sectionalism both make it difficult to integrate the trans-disciplinary teams, directly exerting influence on the effect of early intervention.

In summary, although a quite effective intervention technology has been concluded gradually for the treatment of millions of children who need early intervention, a system has not formed, with some operation technologies too scattered to guarantee the service quality. I suggest that the government introduces related policy, laws and regulations to ensure the universality and effectiveness of the early intervention and construct the implementation plan for the service to enhance the exchange and cooperation between organizations and professions and form consensus and tacit understanding between relevant professions and personnel to make up the insufficient manpower and resources; moreover, the assessment methods and instrument for children development should be integrated to facilitate the referral of individual cases and resource sharing.

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