

## Original Articles

# Cognitive Outcome of Children with Developmental Delay in Hong Kong

KML TANG, TYK CHEN, VWY LAU, MMF WU

### Abstract

**Objective:** To determine the cognitive outcome of young children with global developmental delay at primary school entry and to examine the parental preference of primary school placement for these children in Hong Kong. **Method:** A retrospective cohort study was done in Child Assessment Service of the Department of Health. Cognitive outcomes of children with various degrees of developmental delay at initial diagnosis were reassessed before their primary school entry in the year 2004 and the parental choice of primary school placement was also analysed. **Results:** 493 children were included in the study. At the initial diagnosis, 60.4% (298) of children were diagnosed to have borderline developmental delay, while 39.6% (195) children were found to have significant developmental delay reaching mental retardation (MR) level. At pre-primary reassessment, among those children with borderline delay, 42.0% (125) were found to have normal intelligence (IQ); 26.9% (80) were found to have limited IQ; while 31.1% (93) were found to have MR. On the other hand, among those with significant developmental delay, 81.0% (158) were found to have MR, while only 9.2% (18) and 9.8% (19) were found to have limited and normal IQ respectively. Half (49.0%) of the parents with children of limited IQ declined remedial service in mainstream schools; while around 40.0% (37.9%) of the parents with children of MR insisted their children to be integrated into normal schools. **Conclusion:** Children diagnosed to have borderline developmental delay during the preschool period had nearly half the chance in catching up of cognitive function at the pre-primary school stage. However, if a child had significant delay at initial diagnosis, there was more than 80.0% chance that the child would have cognitive impairment at primary school level. Since a substantial proportion of parents with MR children favored school placement in mainstream schools, the need for providing support to mainstream schoolteachers in managing the educational needs of these children must be addressed.

**Key words** Cognitive outcomes; Developmental delay; Mainstream school; Mental retardation

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### Introduction

Developmental delay (DD) is a term that is commonly applied to the preschool child of less than 5 years old, whose developmental level is substantially behind the average expectations of children of the same age in two or more developmental domains.<sup>1</sup> These domains include cognitive and intellectual, gross motor, fine motor, language, social and adaptive development.<sup>1</sup> In the United States, there is

no formal statistics on the precise prevalence of DD, however, by estimating from the prevalence of mental retardation in the general population, around 1% to 3% of preschool children are expected to have different degrees of DD.<sup>2</sup> In Hong Kong, around 1500 children were newly diagnosed to have DD in the year 2004. This number accounted for one quarter of the referrals to the Child Assessment Service (CAS) of Department of Health, which was a substantial proportion of the new referrals to the service.<sup>3</sup>

In our locality, children diagnosed to have DD in CAS will be referred to Social Welfare Department for arrangement of early intervention programs. In general, children with borderline to mild DD will be suggested to train in Integrated Child Care Centres (ICCC) for inclusive education in normal settings. While children with significant global delay whose developmental domains are markedly behind age expectation will be recommended to attend Special Child Care Centres (SCCC) for individualised training programs, in which intensive support from physiotherapists, occupational therapists and speech therapists are available. Overseas evidence shows that children with DD can benefit from early intervention and diagnosis with improved outcome, especially when they came from socially-deprived families.<sup>4,5</sup> This is consistent with some parents' expectation that children with DD in the early years of life will catch up by school age.<sup>6</sup> However, in other cases, DD is often an early warning sign of later developmental problems such as mental retardation, specific language impairment or other developmental disorder.<sup>7,8</sup> Therefore, data on cognitive outcome or prognosis of children with DD can provide valuable information on future resource allocation and educational planning at schools. As in the cases of very low birth weight children with DD, multiple problems in spatial, verbal, phonological processing usually become apparent at school age because these processing require more abilities in different areas.<sup>9</sup>

During the last decade, there has been a widely accepted view in both the Western and Asian countries that children with disabilities should have the equal chance to receive education in a least restrictive environment. Implementation of inclusive practices is becoming a worldwide movement.<sup>10-12</sup> The involvement of parents in this inclusion process is essential.<sup>13</sup> With the introduction of inclusive education in 1997 in Hong Kong, local mainstream schools are encouraged to include children with special needs into their schools or regular classes. Schools are given additional resources to accommodate children with special needs. Therefore, parental choice of educational placement for

children with special needs has a significant impact on the resource allocation for supportive services in schools.

Although DD is a common paediatric problem and its developmental outcome has great implication on resource management, there is paucity of local study documenting the development course. The present paper reported a retrospective cohort study, which is the first attempt of similar nature in Hong Kong. It aimed to examine the cognitive outcome of children diagnosed with DD at pre-primary one. Parental choice of school placement of these children would also be examined and the possible implication would be discussed.

## Methodology

### Subjects

A retrospective cohort having clinical encounters in the year 2003/04 was retrieved from the information system of CAS based on five inclusion criteria. In order to be selected, a child had to: (i) be age-appropriate to primary one entry in the coming school year 2004, (ii) be less than 5 years of age at initial diagnosis, (iii) have undergone medical evaluation of developmental delay by the developmental paediatricians in CAS, (iv) be without autistic spectrum disorder; and (v) be willing to be reassessed in CAS. This cohort all received preschool training in ICCC or SCCC. Four hundred and ninety-three children, in which 364 were boys and 129 were girls, were included as a result.

### Procedure

Children included in the present retrospective study were scheduled for a review assessment on their cognitive functioning between the ages of 4 and a half years to 6 years old, before primary school entry. The objectives of the pre-primary assessment are two-folded. Firstly, it reviews the developmental progress of these children after preschool intervention. Secondly, it is for diagnosis and recommendation of suitable educational placement for children with persistent special education needs. Depending on their age and abilities, children underwent either a detailed developmental assessment conducted by developmental paediatrician, using Griffiths Mental Developmental Scale (GMDS);<sup>14</sup> or a standardised intellectual assessment conducted by clinical psychologist, using either Standard Binet Intelligence Scale: Fourth Edition (SB:FE),<sup>15</sup> or Hong Kong Wechsler Intelligence Scale for Children (HK-WISC).<sup>16</sup> This age range was chosen

because it is the usual age before the primary school entry, which is a key childhood developmental and social milestone at which children's successful adaptation is essential for their future success.

As there is no Chinese norm-referenced developmental test available, CAS has adopted GDMS in developmental assessments. This assessment scale tests on five aspects of child development, including locomotion, personal-social skills, hearing and speech, eye-hand coordination and the overall performance. After the assessment, a developmental quotient (DQ) that reflects the age-specific developmental level of the child would be obtained. In the present study, DD is defined as developmental levels substantially behind the average expectation of children of similar age in two or more developmental domains, including cognitive and intellectual, gross motor, fine motor, language, social and adaptive development.<sup>1</sup> Significant delay is taken to refer to scores 1.5 to 2.0 SD below the mean of GDMS (i.e. DQ <70).<sup>14,17</sup> Whereas borderline delay is taken to refer to scores 1.0 to 1.5 SD below the mean of GDMS (i.e. DQ 70-79).<sup>14</sup>

Intelligence level is measured by intelligence quotient (IQ). The choice of IQ tests (HK-WISC vs SB:FE) highly depends on the level of cognitive functioning and language level of the child being assessed. In some cases, both the HK-WISC and SB:FE were administered to the child to achieve better estimation of his/her cognitive functioning level. IQ below 70, between 70 and 79, and above 79 is defined as "mentally retarded", "limited intelligence", and "normal intelligence" respectively.<sup>15,16</sup>

After the assessment, a conference involving parents and the examiner would be conducted to have a shared understanding of children's cognitive profile. The examiner would give advice on suitable school placement and supportive service for the children. Referral for the recommended service was then made with parental consent. The clinical profile and referral information related to the children would then be entered into the information system of CAS.

Data of the present study was retrieved from Child Assessment Service Information System (CASIS), the information system of CAS. Medical files of cases selected were then reviewed by a team of one paediatrician and two clinical psychologists on a case-by-case basis.

## Data Analysis

Statistical Package for Social Science (SPSS, version 10) was used to analyse the data. Information about clinical profile of children, including demographic data, initial

diagnosis, types of preschool attending, and cognitive outcome before their primary school entry, was analysed. The present study also reported children's familial pattern including parents' educational level and occupation, and parental choice on school placement.

## Results

### *Characteristics of Subjects At Initial Assessment*

The characteristics of the subjects were shown in Table 1. Among the 493 subjects, 298 children (60.4%) were diagnosed to have borderline developmental delay at the initial diagnosis, while 195 children (39.6%) were found to have significant developmental delay at mental retardation (MR) range. The male to female ratio was about 3:1. 2.6% and 5.7% of these children had family history of mental disorders and MR respectively.

At the time of review assessment, the mean age of the subjects was 4 years 10 months old (4.85 years  $\pm$  SD 0.3 years). Around 60% of them (58.8%) were studying in ICCC, while the remaining 40% (41.2%) were studying in SCCC.

The socioeconomic status of the subjects was reflected by the education level and the occupation of their parents. Around three quarters of the parents had completed secondary school or above (77.1% for fathers and 77.9% for mothers). Around 17% were at primary school level or below (17.0% for fathers and 17.7% for mothers). Nearly 45% of their fathers (44.2%) were employed as non-manual workers, which comprised of "managers and administrators," "professionals", "associated professionals", "clerks" and "service workers".<sup>18</sup> More than half of the mothers (61.4%) were housewives.

### *Pre-primary Cognitive Outcomes*

At pre-primary reassessment, among the total of 493 subjects, 29.2% (144) were found to have normal intelligence (low average or above), 19.9% (98) were found to have limited intelligence, while 50.9% (251) were found to have MR. The male to female ratio in MR group was 2.4:1.

For those with the initial diagnosis of borderline delay, 42.0% (125) were found to have normal intelligence, 26.9% (80) were found to have limited intelligence, while 31.1% (93) were found to have MR (Figure 1). On the other hand, among the 195 children with significant developmental delay, 81.0% (158) were found to have MR, while only 9.2% (18) and 9.8% (19) were found to have limited and normal intelligence respectively (Figure 1).

**Table 1** Characteristics of subjects

	Frequency (Total = 493)	Percentage
Cognitive level at first assessment		
Borderline delay	298	60.4
Significant delay	195	39.6
Cognitive level at reassessment		
Normal intelligence	144	29.2
Limited intelligence	98	19.9
Mental retardation	251	50.9
Sex		
Male	364	73.8
Female	129	26.2
Family history of mental disorders		
Present	13	2.6
Absent	480	97.4
Family history of mental retardation		
Present	28	5.7
Absent	465	94.3
Type of preschool attending at reassessment		
Integrated Child Care Center (ICCC)	290	58.8
Special Child Care Center (SCCC)	203	41.2
Father's education level		
Matriculation of above	87	17.7
Secondary school level	293	59.4
Primary or below	84	17.0
Unknown	29	5.9
Mother's education level		
Matriculation of above	68	13.8
Secondary school level	316	64.1
Primary or below	87	17.7
Unknown	22	4.4
Father's occupation		
Non-manual	218	44.2
Manual	190	38.6
Non-working	43	8.7
Unknown	42	8.5
Mother's occupation		
Non-manual	158	32.1
Manual	13	2.6
Non-working	303	61.4
Unknown	19	3.9

Mean age at reassessment = 4.85 years  $\pm$  SD 0.3 years

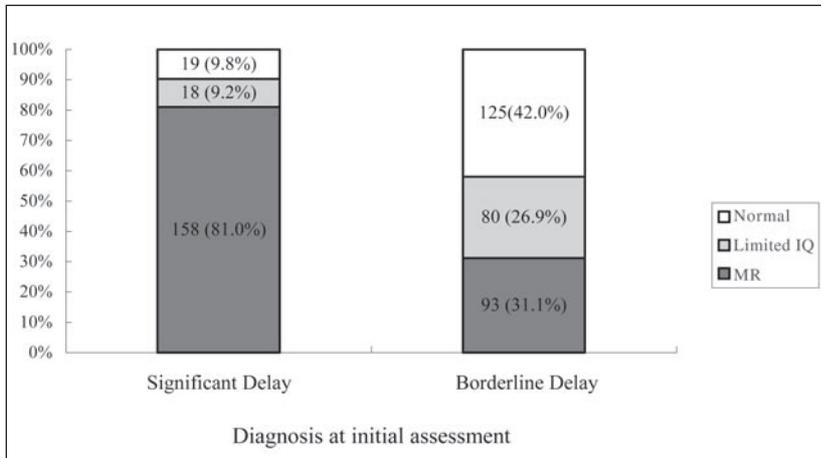
The cognitive outcome of the subjects (MR vs non-MR) was not correlated with the socioeconomic status (using paternal occupation and maternal education) of the parents in this study ( $P=0.56$  &  $0.67$  respectively).

**Parental Decision in Primary School Placement**

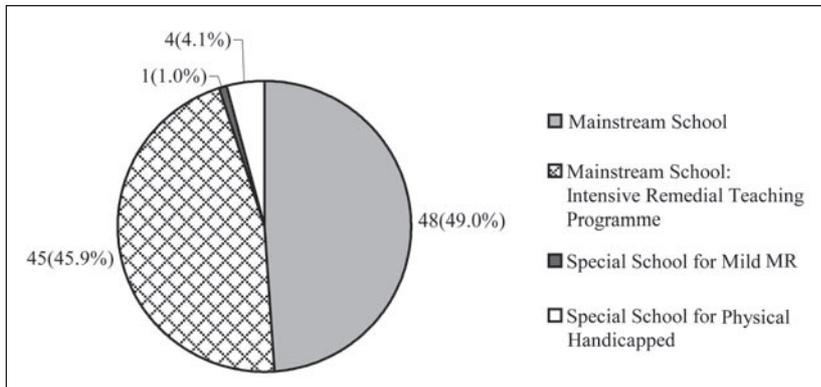
Figure 2 shows the results of primary school arrangement for children diagnosed to have limited intelligence after

pre-primary assessment. 45.9% of the parents agreed to the provision of intensive remedial teaching to their children in mainstream schools. However, 49.0% of the parents declined to notify the school principals and the Education and Manpower Bureau for the necessity of remedial service in the new schools.

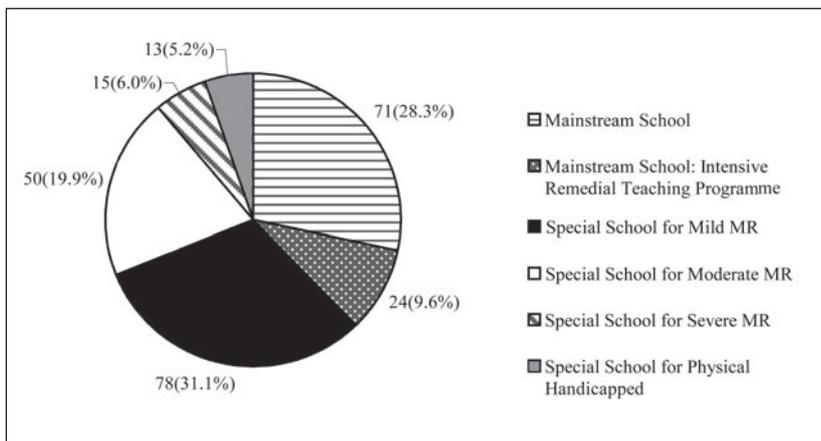
Figure 3 shows the pattern of primary school arrangement for children diagnosed to have MR. 62.1% of



**Figure 1** Cognitive outcome at pre-primary assessment.



**Figure 2** Parental decision in primary school placement for children with limited intelligence.



**Figure 3** Parental decision in primary school placement for children with mental retardation.

the parents agreed to let their children study in special schools. However, 37.9% of the parents insisted their children to be integrated into mainstream schools. Near three quarters (71 out of 95) of them declined to have intensive remedial service at mainstream schools. Among those parents who declined any special educational support to their children, more than half (62.0%) of these children were diagnosed to have mild grade MR (Table 2).

The decision about school placement was also not correlated with the socioeconomic status of the parents in this study ( $P>0.05$ ).

### Discussion

Analysis of the developmental profiles of the cohort suggested that 60% suffered from borderline delay and only 40% of these children suffered from significant developmental delay at first assessment. Such finding is comparable to the normal distribution of the intellectual functioning of the general population, where significantly delayed or mentally retarded portion comprise only 2-3% of the whole population.<sup>19</sup>

Analysis of the data on sex ratio of children who suffered from MR at outcome also revealed interesting findings when compared to the statistics reported in the United States. According to the estimation from DSM-IV, the male-to-female ratio for MR is estimated to be around 1.5:1.<sup>20</sup> Data from the present study revealed a higher ratio of 2.4:1. A possible reason is that boys are more easily identified by parents as having behavioural problems or speech delay. Thus more boys were referred to our service for these salient reasons. However, such speculation needs further investigation and confirmation with future study.

In addition, findings from this study also revealed that most parents who received our services were more educated and higher social status, as reflected by their occupation, than the general population.<sup>3</sup> Only a small proportion of affected children came from at-risk families with social and familial difficulties. This finding is surprising to us. As it is well known that families with socio-familial risk factors are prone to have children with MR,<sup>21,22</sup> it is expected they would be seen more often in service like CAS. This unanticipated observation may be accounted by the fact that as the economy and information technology of Hong Kong is getting more and more developed, information related to developmental problems in children are proliferating and becoming more accessible. Citizens can

**Table 2** Distribution of intelligence status for those children whose parent declined special education support in mainstream school or special school

<b>IQ status</b>	<b>No. of cases</b>	<b>Percentage</b>
Mild MR	44	62.0
Moderate MR	15	21.1
Severe and profound MR	12	16.9
Total	71	100

IQ=Intelligence; MR=Mental retardation

be more aware of the health concerns of children and developmental problems in children. This is especially true for educated parents in the middle class as they, with higher social status, are likely to have more access to information and be more aware of the health issues related to developmental problems in children. Nevertheless, despite the improved economy, there is still a group of deprived, at-risk families that are really in need of all health services. Future direction for our service is to focus on further promotion of paediatric health awareness to those at-risk families with lower social status.

Concerning the developmental outcomes at pre-primary school entry, our overall findings generally suggested that preschool children with DD might present with different outcomes, depending on the severity and nature of the developmental problems. A remarkable proportion of children with borderline delay at preschool years were found to have borderline range or normal intellectual functioning at pre-primary review. This finding is consistent to the findings from previous study that children with DD may present with positive outcomes with early intervention.<sup>4,5</sup> For children who suffered from global delay or significant degree of delay, our findings suggested that most of them (more than 80%) were more likely to be diagnosed to have MR or limited intelligence when they were approaching the stage of primary education. Again, this finding is consistent to the general finding reported by other researchers that children with global delay are more likely to develop into a more persistent or generalised form of developmental disorder, such as mental retardation.<sup>23,24</sup> However, one interesting finding in this study was that a small percentage of children (9.8%) who were identified to have significant developmental delay at initial diagnosis showed to have normal intellectual abilities later. By speculation, a portion of these cases were diagnosed in the infancy period, during which developmental performance depended heavily on motor function rather than cognitive

function. If their motor development were weak, they might present as significant developmental delay. However, during pre-primary reassessment, testing was more focused on cognitive function. This group of children was then found to have normal intelligence. Whereas, another group appeared to come from socially deprived families or minority groups of our society. They seemed to be the most responsive group to the early intervention for special preschool children as stated in some overseas studies.<sup>4,5</sup> However, this suggestion cannot be conclusive due to relatively small number of cases in our study. Therefore, further study is needed to explore the characteristics of this group of children.

In view of the rapid change of clinical picture in preschool children with DD, there is a service implication to conduct periodical review to investigate the developmental progress of these children, especially before the key developmental checkpoints (e.g., before starting primary education). This is especially helpful for monitoring and service allocation purposes. For children with more significant degree of delay, there may be needs for further effort to prepare their parents to understand the possible developmental pathway and the options of special educational services available to their children.

Concerning the findings on parental choice on educational placement, where many of them were in favor of inclusive education, this finding is not surprising. Observation from clinical practice suggested that such trend was more obvious in parents whose children were diagnosed to have milder form of MR. Our findings are quite similar to those in other developed countries, where inclusive education has been carried out for many years; parents of children with mild disabilities give more supportive views regarding inclusion, especially when their children are at elementary school-age.<sup>13,25</sup> However, our findings revealed a worrying trend that a remarkable proportion of these parents were reluctant to disclose the diagnosis of the developmental problems of their children to the school personnel and to accept referral for special educational supportive service in mainstream schools. Stigmatisation as well as the parental concerns on the attitude of primary school personnel and schoolmates to their children with special needs may be the possible explanations for this finding. Parents with reservation to disclose the special needs of their children may present a special challenge to local schools in service planning and follow-up management for those children.<sup>10,26</sup> Therefore, the school adjustment and learning progress of these children at

primary school needs to be monitored and timely referral to special supportive services in mainstream schools or training services from special schools should be re-initiated when necessary. Since the continuous parent involvement and support is critical for successful implementation of inclusive education,<sup>25</sup> it highlights the importance of counseling to parents about the acceptance of their children's developmental problems, promotion of parental understanding on available options on educational placement, and preparing them for a helpful attitude in working with the school personnel.

Some limitations of this study should be mentioned. Since this study was a preliminary attempt to study the developmental profiles and the developmental outcome of children with history of developmental delay; data were collected retrospectively from the database of CAS, in which some important neurodevelopmental factors, in relation to the outcomes could not be obtained. Also, not all the suitable cases diagnosed in CAS were included in this study, as many of them dropped out for various reasons. It may be interesting for future study to be a well-designed prospective cohort and to identify further neurodevelopmental factors related to onset of mental retardation and protective factors related to better developmental outcomes (especially for those children with significant developmental delay). Moreover, as pointed out by other researchers,<sup>23,24</sup> the relationship among early history of developmental delay, other functional outcomes (e.g. learning, social and adaptive outcome) may be a further direction for study, as presence of early developmental delay can be an early sign of other developmental disorder and persistent difficulties in learning, social and behavioural aspects.

## Conclusion

Children diagnosed to have borderline developmental delay during the preschool period had nearly a 50% chance of catching up in terms of cognitive function at the pre-primary school stage. However, if a child had significant delay at initial diagnosis, there was more than 80% chance that the child would have cognitive impairment at primary school level. Since a substantial proportion of parents with MR children favoured school placement in mainstream schools, the need for providing support to mainstream schoolteachers in managing the educational needs of these children must be addressed.

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