

UNIT NO. 6

ASSESSMENT OF ACTIVITIES OF DAILY LIVING IN CHILDREN AND INFANTS WITH DEVELOPMENTAL DISABILITIES

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ABSTRACT

Developmental disabilities are a group of chronic disorders of early onset estimated to affect 5 to 10% of children¹.

Children with developmental disabilities often show a variety of associated impairments that possibly lead to a lifelong need for additional care. These impairments may lead to limitations in the capacities of the child. According to the International Classification of Functioning, Disability and Health (ICF), capacities describe the individual's ability to execute a task or an action. Capacities are defined as the highest probable level of functioning that a person may reach in a given domain at a given moment in a 'standardised or assumed' environment. Limitations in the capacities of these children lead to the need for additional care. Stein et al defined this additional care as 'dependency on medication or special diet, medical technology, assistive devices, personal assistance, need for medical care or related services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions or accommodations at home or in school'².

In a study of the families of 40,000 disabled children in the UK, the majority of the children required extra assistance or supervision with multiple areas of daily life. The study also indicated variety in extra care tasks undertaken (physical help, supervision, guidance) and causal factors (physical limitation, cognitive difficulties, behavioural problems). In particular, the findings indicated that parents want professionals to recognise and offer explicit acknowledgement of the extra care they give their disabled children³.

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INTRODUCTION

All children have a right to care by a parent or trusted adult. As infants, this care extends to every aspect of the child's life: bodily functions, and physical, mental and emotional development. As the child grows the care required changes and generally diminishes. Severely disabled children require the same care and parenting as other children, with the addition of extra care due to impairments or chronic ill health.

The extra care required by these children may arise from delayed development of self-care skills and/or a need for special care. Delayed self-care skills mean that care needs -which are expected to diminish- persist. Special care needs 'go beyond the bounds of ordinary parenting', for instance involving ventilators or feeding tubes.

Family circumstances are also important. Families often have more than one child, and sometimes more than one disabled child. Single parents often care for their disabled children alone.

INDEPENDENCE IN ADL IN INFANCY AND CHILDHOOD

Filling in the boxes in the form would probably not be of relevance for many of the children, and especially the infants. Whether a child is independent in an aspect of ADL would be dependent on his chronological and developmental age, as well as cultural and other environmental factors. In typically developing children, there is generally an age range at which a certain ADL is achieved, but again, external cultural and other environmental factors need to be taken into consideration. In a study on normal Hong Kong Chinese children, some gender and culturally specific aspects (e.g. the presence of a maid at home, early attendance at preschool) were found to impact on the performance of functional skills. In general, girls mastered self-care and communication competencies before boys⁴.

Crucial to measuring functional limitations is defining essential daily tasks. These may include self-care activities of feeding (using a cup, spoon, and fork), grooming (washing face and hands, brushing teeth, combing hair), dressing upper body (shirts/blouses), dressing lower body (underwear, pants, shoes and socks), adjusting clothes, maintaining bladder and bowel continence, and wiping after toileting. Motor activities include changing positions from chairs, getting on and off toilets, getting in and out of the bathtub or shower, walking indoors and outdoors, and ascending and descending stairs.

The list of these activities reflects that during a typical day a child must complete a meal independently using appropriate utensils or be assisted in feeding. The child, during a typical day, will wash hands and face, brush teeth, comb hair, or be assisted in these areas. A child, on a typical day, will dress and maintain continence or require assistance or diapers. A child will generally ambulate indoors and outdoors, get in and out of chairs, on and off toilets, in and out of showers, negotiate stairs, or be assisted with these tasks.

EXISTING INSTRUMENTS

Currently, paediatric health professionals have several choices for adaptive-functional instruments. These include the WeeFIM (Functional Independence Measure), the Pediatric Evaluation of Disability Inventory (PEDI), the Battelle Developmental Inventory (BDI), and the Vineland Adaptive Behavior Scales (VABS). The PEDI, BDI and VABS are maximum data sets and involve detailed and extensive queries of self-care, mobility, communication and social items. On average, they require >30 minutes of interview time and complex scoring^{5,6}. The WeeFIM

is useful in assessing functional independence in children aged 6 months to 7 years (up to 21 years in people with developmental disabilities), and can be administered by a trained interviewer in approximately 15 minutes⁷. There also exist some simpler screening questionnaires, such as the measurement of activities of daily living (M-ADL), which are currently being tested. The M-ADL does not require trained interviewers, and takes about five minutes to administer⁸.

FUNCTIONAL ASSESSMENT

Washing/Bathing

Typically developing children in Singapore often start bathing independently from the age of five or six. Children exposed to day care may bathe independently earlier.

Extra care with washing may be because of a physical inability to wash or extra care for delicate skin. Frequent vomiting, diarrhoea, or weeping wounds necessitate repeated washing.

Dressing

From about 18 months, toddlers often assist with dressing and undressing, taking off shoes. By the age of three, he is able to pull his pants down and up, but needs help with buttons and other fastenings. Most five-year-olds are able to undress and dress independently.

Extra help when dressing may include practical help because of stiff or floppy limbs, repeated changes due to incontinence or dribbling, or guidance for a visually impaired child.

Feeding

An 18 month old toddler can hold a spoon and get food safely to his mouth, although he may also play with the food. He is able to hold his cup between both hands and drink without much spilling. By the age of two, he is able to feed himself competently with a spoon, but is easily distracted. He is able to lift a cup and drink well without spilling, and replace the cup on the table without difficulty. He is able to ask for food and drink. By the age of four, he is able to eat skillfully with a fork and spoon.

A child who finds chewing and swallowing difficult or requires tube feeding needs extra care at mealtimes, while children with behavioural disorders or insatiable (e.g. in Prader Willi Syndrome), or inappropriate (e.g. Pica) appetites require close supervision.

Toileting

Many toddlers begin to give notice of urgent toilet needs by restlessness and vocalisation. Bowel control may be attained but this is variable. They may indicate wet or soiled pants.

Encopresis is defined as regular soiling of the underwear in children aged four years and older, with no organic disease. The soiling can range from staining the underwear to semiformal or formed stools. Enuresis is defined as a lack of urinary continence beyond the age of four for diurnal enuresis, a lack of urinary continence beyond the age of six for nocturnal enuresis, or the loss of continence after at least three months of dryness.

Young disabled children may need extra care when toileting due to diarrhoea or catheterisation and although most children are toilet trained by the age of three, this process is often prolonged or unsuccessful for disabled children.

Transferring and Mobility

Toddlers from the age of about 18 months are generally able to walk well and run carefully, with rapid improvement of locomotor skills from about two and a half years. Two-year-olds enjoy climbing, and will climb forward into an adult's chair, then turn round and sit. By the age of four, they are able to walk or run alone up and down stairs, one foot to a step in adult fashion.

Inaccessible toilet facilities may mean an older physically disabled child continues to require adult assistance, while other disabled children find it hard to manage personal hygiene alone.

Additional Care for children with special needs may also include the following:

- Extra care at night, e.g. turning an immobile child, giving medication or tube feeds
- Supervision for children with special needs when they are awake, as some may have frequent seizures, or lack an awareness of danger
- Behavioural problems ranging from inconsolable and constant crying in younger children to self harm, destructiveness and violent or attention seeking behaviour in older children.

TYPES OF DISABILITY IN CHILDREN AND INFANTS

In the form for application for FDW levy concession for persons with disabilities, the disability types have been divided into six main categories.

Physical

These would include congenital structural malformations as well as neuromuscular disorders, which affect motor function. In general, these disorders present fairly early, e.g. structural malformations such as spina bifida and arthrogryposis multiplex congenital would be picked up in the neonatal period. Other 'physical' disabilities such as cerebral palsy, Duchenne Muscular Dystrophy and other neuromuscular disorders generally present in the first to third year of life.

Intellectual

There is some confusion about the label "Global Developmental Delay" (GDD). This is a subset of developmental disabilities defined as significant delay in two or more of the following developmental domains: gross/fine motor, speech/language, cognition, social/personal, and activities of daily living. GDD describes a clinical presentation that has a heterogeneous aetiological profile and is associated with age-specific deficits in adaptation and learning skills. Those deficits are evident in comparison with the skills attainment of chronological peers. The term GDD is usually reserved for younger children (i.e. typically less than five years of age), whereas the term mental retardation is usually applied to older children when IQ testing

is more valid and reliable. However, a child with the clinical picture of GDD is not necessarily destined to be mentally retarded. Infants and children may have GDD owing to conditions such as cerebral palsy, certain neuromuscular disorders, and other conditions such as early environmental deprivation, yet when they are old enough to measure cognitive level they do not score in the mentally retarded range¹.

Autism Spectrum Disorder

As this is a 'spectrum disorder', the symptoms, abilities, and characteristics are expressed in many different combinations and in any degree of severity. Hence, children with autism vary widely in their cognitive, language, and social abilities, with a variety of strengths and weaknesses. At one end of the spectrum, we may find a mute child, crouched in a corner of the room, spinning a paper clip over and over again for hours; at the other end of the spectrum is a university researcher in the Mathematics department.

Their major deficit is in interactive social relationships and social communication, both verbal and non-verbal. Many children with ASD also have restricted interests and activities.

Sensory

This category is generally fairly straightforward, and would include children with a single sensory impairment, such as Visual or Hearing Impairment.

Multiple Disabilities

Children with multiple disabilities, such as coexisting cerebral palsy with mental retardation, or children with two sensory impairments, would fall into this category.

ILLUSTRATIONS USING CASE STUDIES

Spina Bifida

V is a 7-year-old Indian girl with T12 spina bifida diagnosed only at delivery. This was closed on day 1 of life. A ventriculo-peritoneal shunt was also inserted for hydrocephalus. She is presently attending primary one at a mainstream primary school, with therapy support from Teach Me services. Her father works shifts as a security guard whilst her mother is a homemaker, and her main caregiver. V has an older brother and a younger sister.

She is able to use a cup, spoon and fork without help; her mother cuts her meat. She independently brushes her hair, brushes her teeth, and washes her face and hands without help. V is able to wash and rinse during bathing; her mother assists in drying. She puts on and removes t-shirts. Her mother helps her in fastening her zippers. V requires a lower extremity orthosis; she is able to perform 75% of the effort of applying it. She is able to put on and take off her shoes and socks. She cannot wipe herself after toileting. Her mother adjusts her clothes after her bowel movements.

V is on Ditropan for bladder spasticity, and uses clean intermittent catheterisation; she successfully passes the catheter half of the time, and has bladder accidents on a daily basis. She uses a bowel catheter, which her mother must administer twice

a week. She has no stool accidents at other times.

V's mother helps her transfer onto the toilet. She cannot do a standing pivot or slide transfer. She can transfer in and out of bed when she is not wearing her brace. V requires a wheelchair for outdoor activity. She does most of the transfer from chair to wheelchair. She has a walker for household use and can safely traverse a room using the walker. V cannot crawl and must be lifted up stairs.

V can understand fully ordinary conversation and follow a three-step related command. She expresses basic needs and ideas about everyday situations clearly and fluently without help. V plays board and card games with her friends without adult supervision. She knows all the rules and can instruct other children in how to play. V recently dropped a plate and made sure her one-year-old brother did not crawl into the glass.

Points to note:

- P Cognitively high functioning child, but needing help with many self care activities.
- P Supportive mother who is enabled, in an intact home environment.

Down Syndrome

AR is a four-year-old Malay boy with regular trisomy 21, delivered at term. He has a surgically repaired atrioventricular septal defect and is the fourth child of mature parents, who are very supportive and understand his disability.

Presently, AR is attending an EIPIC programme twice a week. He walked independently at age two, and has a steady gait. However, he is unaware of danger, and often climbs onto tables and chairs, to look out of the window. He is able to address his family members, and uses mainly single words, having difficulty with receptive and expressive language skills. His attention span is short, and he is unable to follow most instructions. His behaviour is often self-directed and he has difficulties with unsupervised play and problem solving. AR needs help with dressing, he is still on diapers throughout the day, and tries to use a spoon to feed himself, but is messy. Bathtime is often prolonged and challenging, as AR often refuses to get out of the bath. AR's mother has reported that it is a challenge looking after him, and that she is often exhausted at the end of the day.

Points to note:

- P Supportive mother, who is not well enabled to care for her son's special needs
- P Behavioural difficulties a challenge to his mature caregiver

Autistic Spectrum Disorder

A is a 13-year-old Chinese girl with Autistic Spectrum Disorder with moderate intellectual disability, diagnosed when she was 3 years old. Her father works long hours as a taxi driver. Her mother is a homemaker, and is A's main caregiver. She has two other younger neurotypical siblings.

A is attending classes in a special school. She takes the school bus, but needs her mother to wait with her at the bus stop, as she sometimes still steps onto the road without looking to see if cars are coming. She is able to indicate some of her basic needs

by gesture or signing, but has no speech. She has learned to wash, dress, and feed herself. She has also learned to cut out shapes with a pair of scissors. However, she has not learned to read, write or speak. At school, she is said to be compliant, and able to follow the school routines and schedules well. Too well, sometimes, as A is upset if there are changes in routine.

A has a flat affect, and when she is at home, often engages in repetitive self stimulatory behaviour, such as rocking. Her favourite activity was, and still is, watching cartoons on television. She replays the same cartoon videotape over and over again.

When she turned 12, A developed epilepsy. This is fairly well controlled on anticonvulsant medication. However, she also began to have more frequent and severe temper outbursts. She would scream, shout, throw objects and even push her mother. Often, it would take more than an hour for A to calm down. It was often difficult for A's mother to tend to her needs and to those of her siblings, as well as the household chores. A was finally brought to see the child psychiatrist, who prescribed medication that has helped her tantrums. A daily routine and structure were also established for A, with scheduled times for waking up, washing, meals and watching television.

Points to note:

- P Although A is a teenager, she requires care that is usually extended to perhaps a four-year-old.

Multiple Disabilities

JX is a five-year-old Chinese boy, delivered prematurely at 24 weeks, birthweight 530g. He has spastic quadriplegic cerebral palsy, with spasticity of all four extremities, microcephaly and cognitive impairment. He is also blind with retinopathy of prematurity, and hearing impaired, on hearing aids.

JX had a stormy perinatal period. He had severe hyaline membrane disease, with recurrent pneumothoraces, needing high frequency ventilation, and hypotension, on dopamine and dobutamine inotropic support. JX subsequently developed necrotising enterocolitis, which was conservatively managed, Stage 3 ROP with plus disease, needing laser photocoagulation, bilateral sensorineural hearing loss. He was finally discharged when he reached a weight of 2 kg, with home oxygen for chronic lung disease. JX was weaned off the oxygen when he was about eight months old. Cranial ultrasound showed bilateral cystic periventricular leucomalacia.

His parents separated a year after JX was discharged from hospital. He had multiple readmissions for exacerbations of his

chronic lung disease. Presently, his mother is working part-time as a sales promoter, and his maternal grandmother takes care of him whilst his mother is at work. However, grandma is in her mid-seventies, and also has medical problems of her own. JX's father does not contribute to or participate in his care.

JX is attending the Programme for Children with Multiple Handicaps at Rainbow Centre. He has minimal self mobility, and spends most of his waking day sitting up in a wheelchair. He is totally dependent in all activities of daily living, and although he has no speech, he is socially responsive and recognises his caregivers.

Points to note:

- P Multiple severe disabilities, long term prognosis quite clear
 - will require lifelong care for most areas of ADL
- P Single parent, with little family or community support

CONCLUSION

Children with developmental disabilities are a heterogeneous group with diverse clinical presentations, difficulties and abilities. It is important to consider each child and family individually. Care should be taken to consider the impact of the child's impairments on requirements for extra care across all areas of daily life, as well as the individual family circumstances.

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LEARNING POINTS

- o Children with developmental disabilities often show a variety of associated impairments that result in a lifelong need for additional care.
 - o Parents want professionals to recognise and offer explicit acknowledgement of the extra care they give their disabled children.
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