



Developmental Delay

an information guide for parents

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We have written this book to answer some of your questions. Every child with developmental delay is different. Some have very mild difficulties, others have more serious problems. Because each child is different, the information is presented in a general way.

The booklet introduces the topic of developmental delay with a brief outline of normal expectations during child development.

This is followed by a description of the term 'developmental delay', including the major causes and various presenting features of children with delay.

There is then information about assessment: how it proceeds, how it may help the family and how it is used to direct families and children to appropriate services. Finally, the booklet details the services available to children and describes how these services assist children with delay.

Please discuss your own child's problems with your therapist, maternal and child health nurse, kindergarten teacher, social worker or doctor. There are often no simple answers to your questions. These people will discuss your concerns with you and may direct you to someone else who can help.

Child development

Development is the process whereby a young baby and child explores and learns and grows into adulthood. Individual skills are built up and combined to produce ever more sophisticated achievements (such as walking, talking, playing, thinking and communicating). Development is a difficult concept and many theories exist to explain how development occurs. Many books have been written to contribute to our knowledge and there is still much to learn about the developing child. Development takes place at the greatest rate in the early childhood years. Many skills emerge during these early years and there is wide variation in the timing of milestones from

child to child. For example, walking may commence anywhere between 9 and 18 months and be considered to be within normal limits; while some children's first words follow their first steps, for others the reverse happens. Yet, regardless of the rate, every child develops continuously according to his or her own pattern.

Despite variability from child to child, there is a general order in the progressive development of individual skills. Simple skills precede the more difficult ones. For example, infants reach out and touch objects before grasping and playing with them. Noises and gestures convey meaning before words are spoken. Toddlers scribble before they begin to draw shapes such as faces.

What is normal

The achievements of the young child are so remarkable that they generally create much excitement for those closest to the child. There is great interest in the child's progress toward each new skill and the more notable achievements (smiling, sitting, walking, talking etc.) are often termed 'developmental milestones'. We know that most children achieve these milestones at around a certain age and this is what we mean when we speak of normal development.

Individuals are outside the 'norm' when they display a rate of development that is faster or slower than most children the same age. Some examples of developmental milestones normally achieved in the early childhood years are listed on the next page.

1st Yr

At the end of the first year the child can usually:

- sit without support
- babble with a wide range of sounds
- make a special sound to attract attention
- look for dropped toys
- clearly distinguish strangers from family
- enjoy simple games like peek-a-boo.

2nd Yr

By two years of age the child can usually:

- walk well
- scribble with pencil and crayon
- use a number of single words
- build a tower of three blocks
- recognise a few pictures of common objects
- imitate simple everyday activities; e.g. feeding a doll
- understand when told not to do something.

3rd Yr

By three years of age the child can usually:

- jump, getting both feet off the floor
- put on and take off some articles of clothing
- draw a circle
- join words into simple sentences
- join in play with another person; e.g. rolling, kicking a ball, pretend play with toys
- assert 'self' by opposing the will of parents
- feel comfortable in familiar surroundings in the absence of parents.

5th Yr

By five years of age the child can usually:

- hop
- hold a pencil with mature grasp
- copy a square
- speak fluently and clearly
- begin to count
- know the names of common colours and shapes
- dress without assistance
- understand the rules of game play (turn taking, 'in' and 'out').

What is developmental delay?

Developmental delay is a descriptive term used when a young child's development is delayed in one or more areas compared to other children.

These different areas of development may include:

- gross motor development: how children move
- fine motor development: how children manipulate objects and use their hands
- speech and language development: how children communicate, understand and use language
- cognitive/intellectual development: how children understand, think and learn
- social and emotional development: how children relate with others and develop increasing independence.

Parents and others become aware of delay when the child does not achieve some or all of the milestones at the expected age. Other children may present with behaviour problems which may be associated with delayed development.

The term developmental delay is often used until the exact nature and cause of the delay is known. The significance of the delay is often only determined by observing the child's development over time.



Transient developmental delay

Some children have a transient delay in their development. For example, some extremely premature babies may show a delay in the area of sitting, crawling and walking but then progress on at a normal rate. Other causes of transient delay may be related to physical illness and prolonged hospitalisation, immaturity, family stress or lack of opportunities to learn.

Persistent development delay

If the delay in development persists it is usually related to problems in one or more of the following areas:

- understanding and learning
- moving
- communication
- hearing
- seeing.

An assessment is often needed to determine what area or areas are affected.

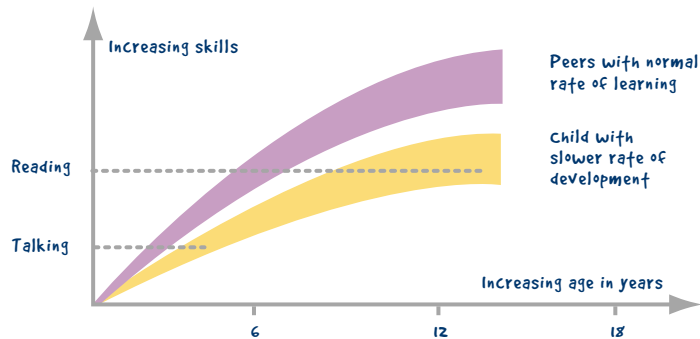


What are the causes of persistent developmental delay?

Disorders which cause persistent developmental delay are often termed developmental disabilities. Examples are cerebral palsy, muscle disorders, language disorders, autism, emotional problems and disorders of vision and hearing. All these conditions can cause developmental delay. However, one of the most common causes is an intellectual disability.

What is intellectual disability?

Children with an intellectual disability show a delay in their understanding of the world and take longer to think and learn new skills, e.g. talking, self help skills such as dressing and eating independently. The age of acquiring a specific skill depends on the rate of learning.



The above diagram illustrates that children with slower rates of learning acquire skills at different ages and the delay often becomes more obvious as the child grows older. The difference in skills, compared to their peers with normal rates of learning, often becomes more obvious as they grow older. For example, a child with a slower rate of learning may have a delay of one or two years in learning to talk but may later show a delay of many more years in learning to read.

There is a wide range in the severity of intellectual disability. Children who have a very slow rate of learning (moderate and severe intellectual disability) often cause concern in the first two years of life.

Some of these concerns may be about slow feeding, lack of sustained interest in toys and people, or a delay in speaking the first words.

Children with a mild intellectual disability may not cause concern until their third or fourth year with a delay in their talking. Yet others may only come to notice in their kindergarten years when their play, self help and learning skills are less well developed than children of similar age. For some children with a very mild intellectual disability the problem may not become apparent until their early school years.

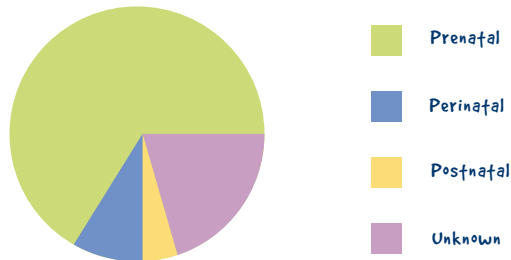
Children with an intellectual disability may also have problems in other areas such as vision and hearing. These problems may affect their learning.

Some children may have epilepsy or may develop it during childhood. Drug therapy may be necessary, and if so, the doctor aims to control the seizures by choosing medication that best suits the child.

A child with an intellectual disability can still learn but needs more time and practice than other children. Like all children they need to feel good about themselves.

What are the causes of an intellectual disability?

The reason or cause is not always known. However over half are caused by factors before birth (prenatal), others by factors around the birth period (perinatal) and some later (postnatal).



This chart shows the timing of the causes of moderate, severe and profound intellectual disability. With the development of new knowledge, the percentage of unknown causes is slowly diminishing. For children with mild intellectual disability there is a larger percentage where the cause is unknown.

The following conditions are sometimes a cause of intellectual disability:

Prenatal (i.e. before birth):

Chromosomal

- Trisomy 21 (Down Syndrome)
- Fragile X Syndrome

Genetic

- Tuberous Sclerosis
- Metabolic disorder e.g. phenylketonuria

Syndromes

There are many syndromes, most of which are rare.

Some examples are:

- Williams Syndrome
- Prader-Willi Syndrome
- Cornelia de Lange Syndrome

Infections

- Rubella virus, Cytomegalovirus

Drugs, toxins

- excessive alcohol

Major structural anomalies of the brain

Perinatal factors (i.e. around birth)

- Lack of oxygen (hypoxia)
- Trauma
- Infections
- Biochemical abnormalities such as low sugar levels

Children with low birth weight are at increased risk of having these complications after birth.

Postnatal factors (i.e. after the birth period)

Head injuries

- motor car accidents
- near miss drowning accidents

Infections such as meningitis and encephalitis

Poisons

For mild intellectual disability the cause is often not known, although it may be caused by any of the factors listed previously.

What is autism spectrum disorder?

Autism spectrum disorder is a condition that describes children who behave in a certain way. The diagnosis may be made when the following are all present:

- major delay or problem in language development
- problems relating to other people
- unusual repetitive behaviours and limited play.

Some children may be affected more severely in one or more areas. The majority of children with autism spectrum disorder have intellectual disabilities and usually present in their second year of life with developmental delay. The causes of autism spectrum disorder include most of those listed for intellectual disability.

How common is disability in childhood?

This is unknown. However, figures are available for some of the conditions causing a major delay, and may vary somewhat depending on the source of information.

Intellectual disability (mild)	Approximately 1 / 100 children
Intellectual disability (moderate/severe)	Approximately 3–5 / 1,000 children
Cerebral palsy	2 / 1,000 children
Hearing impairment requiring a hearing aid	1–2 / 1,000 children
Blindness/severe visual impairment	3 / 10,000 children
Autism spectrum disorder	5–20 / 10,000 children

What is assessment?

The word 'assessment' may be a frightening term for families, as it can imply a sort of 'test' which the child is about to pass or fail. This is not the case.

Families find assessment useful in answering their questions and assisting them to plan for their child. Assessment is aimed at defining a child's strengths and weaknesses.

Parents should always feel free to discuss the assessment procedure with the staff involved. Parents are usually the best observers of their children. Their contribution to the assessment is important. They need not feel apprehensive about asking for a second opinion.

The initial stage of the developmental assessment is often with a paediatrician (children's medical specialist). During the assessment, the doctor takes a medical history, observes the child, does a physical examination and may order some relevant investigations, for example, blood and urine tests. The doctor may carry out or recommend testing of vision and hearing.

The next stage aims to gather information about the child's skills across all areas of development, and to understand how the child learns and relates to the family and those around him or her. This will involve the child and family being seen by one or more of the following: occupational therapist, speech pathologist, physiotherapist, psychologist, teacher and social worker.

Children are observed playing and interacting with others. Depending on age and development, they may be given a series of tasks such as completing puzzles, naming pictures or climbing steps.

The assessment is very helpful in beginning to understand the child's development. However, it is also important to remember that an assessment provides only one example of the child's ability over a relatively short period of time. As children progress their needs change. Those working with them will monitor progress and assessments will be repeated when necessary.

Where is the assessment carried out?

It may take place:

- in a local community setting such as day care centre, community health centre, or preschool
- in a hospital with paediatric and therapy departments. Some hospitals have assessment teams
- in the home. Some early intervention teams have staff who visit the home and carry out the assessment there
- at a centre, such as a specialised preschool or a facility for children with disabilities.

How long does the assessment take?

The assessment may be completed in a single session or over a number of sessions on several days.

What are the needs of the child with developmental delay?

The child with developmental delay has the same needs as any other child. All children benefit from a warm, secure and nurturing environment. They need to feel accepted with their individual patterns of strengths and weaknesses. This is important for the development of self-esteem, which builds confidence for learning new skills.

Children with delay learn in a similar way to all children but usually take longer to develop new skills.

Many children with developmental delay will need extra help in one or more areas of their development.



They need:

- to hear language which is appropriate to their understanding
- extra time to learn and practice new skills
- to have tasks simplified
- to know that their efforts are valued
- a variety of ways to learn, such as touching, looking and listening.

Therapists and teachers provide suggestions and advice but children learn most skills from their family in the early years of life. Professionals work in partnership with parents in early intervention programs, helping them understand their child's development and special needs.

Do children with developmental delay have behaviour problems?

Behaviour problems are reported by many parents at some stage during childhood. Children with developmental delay are at increased risk of behaviour problems.

When a child displays signs of developmental delay, parents and other care givers begin to adjust to the individual needs of their child. Often, this involves some revision of previous expectations. The task of adjustment may at times cause feelings of failure and frustration in both child and parent. Parents may be uncertain whether their reactions are over-protective or too demanding.

Where a delay exists it is more likely that families may not understand the child's intention or capability. For example, children who have difficulty remembering

instructions, may be expected to have fully understood when they have not done so. On the other hand, children who cannot talk may be able to understand, although families may not always be aware of this. The mismatch between expectations and abilities can contribute to frustration for these children and for those around them. This leads to anxiety and uncertainty and may result in behaviour problems.

Where uncertainty or frustration persist or when behaviour problems fail to resolve, it is generally helpful for families to talk about these difficulties with one of the workers who is familiar with their child.

What are the needs of the family?

The impact on a family of having a child with any sort of difficulty, can never be underestimated. Family members experience emotions such as anger, grief, disbelief and isolation. These emotions are often very intense at the time of diagnosis and may recur over time.

Children with a severe delay may need a lot of assistance with daily living skills such as eating, talking and dressing. This can place enormous stress on the family.



There are a large number of hidden financial costs. These include visits to doctors and other professionals, special equipment, maybe extra nappies, and extra child care.

Each family will have their own individual needs. However for most families their needs will include:

1. Having their questions answered. It is sometimes helpful if parents write down questions which they can then have addressed when they see someone about their child.
2. Support in understanding the nature of the child's delay. This support will include the opportunity to share the feelings, hopes, and fears that they have for their child. Support may be from other family members, friends, parents with similar experiences and professionals.
3. Information about services, and assistance gaining access to them.
4. Information and skills to help them assist their child in the best possible way.
5. Having a break. Time off from childcare is important for most parents. Where the child's daily needs place extra demands on time and energy this is even more important. A break enables families to have a rest and to spend time doing other things.

Who is available to help my child?

Children with developmental delay can benefit from a wide variety of experiences within their family and local community. Additionally, a number of professionals work specifically with these children. Depending on needs, some children may be seen by nearly all of these people, others by only one or two. Different professionals may be helpful at various stages of the child's development.

Some of the people involved are:

1. **Parents** are the most important people of all as they hold the most knowledge about their child. Parents are able to incorporate many of the suggestions made by therapists and teachers into the daily routine.
2. **The family doctor.** Children with developmental delay have the same health needs as other children of a similar age. The family doctor may also know the whole family, and be able to provide support and encouragement.
3. **The paediatrician** is a doctor who specialises in children's health and development. The paediatrician works closely with others and can make referrals to appropriate specialists when necessary.
4. **Nurses** can provide assistance in various ways. Maternal and child health nurses monitor children's early development and support parents who are concerned about their child's development. They are able to provide advice and information about health and behaviour problems. School nurses, either in mainstream or special schools, are able to address everyday health issues such as bowel and bladder

management. Other community nurses, whether in hospitals or community health centres, may provide advice in areas such as epilepsy management and constipation. The Royal District Nursing Service supports families at home following medical procedures or where ongoing medical or nursing interventions are required. Nurses may also be helpful in liaising and obtaining appropriate health care services for your child.

5. **Therapists** are skilled in child development and provide advice and/or treatment sessions. They may work with children and their parents either individually or in small groups. Those most commonly assisting children with developmental delay are physiotherapists, occupational therapists, and speech pathologists. Not every child needs to have assistance from all of these people. However, they often work together in planning or providing treatment.

Therapists aim to teach parents how to best help their children learn all the practical skills needed for living. All young children learn through play and this principle is used when advising parents about the best way to encourage their child's development.

Highlighted on the next page are the special areas in which each therapist works.

5a) **The physiotherapist** provides advice and/or treatment designed to enable children to achieve their own level of functional motor skills, e.g. sitting or standing. This level of achievement will vary from child to child.

Toys, games and specialised equipment are used to encourage the development of the child's motor skills, in conjunction with specific handling skills.

The physiotherapy program becomes part of the child's activities during the day, as parents are shown the best way to assist their child during day to day care and play.

5b) **Occupational therapists** provide advice and/or treatment sessions aimed at encouraging children to use their hands to reach, hold, and manipulate; therefore enabling them to participate in activities of daily living including self-care and play. They assess children in all areas of development and provide advice about appropriate toy and play activities and specialised equipment for activities such as dressing, toileting and bathing.

5c) **The speech pathologist** sees children with difficulty talking or understanding speech. Advice is given to families on how to encourage language development. Sometimes alternate methods of communicating, such as using signs or a communication board, will be recommended to assist in the development of communication skills. Speech pathologists also work with children who have difficulty eating and drinking, or who dribble excessively.

6. **The social worker** provides counselling and support for families who have children with special needs. Information about early intervention programs and entitlements and help in finding the most

appropriate services, is also given. The social worker can also provide information for parents who wish to meet others with similar experiences.

7. **The psychologist** monitors children's overall development by observing and understanding progress in learning alongside emotional and social development. The psychologist may also be available to help if there is some concern about a child's emotional well-being and behaviour or difficulties within the family.

8. **Special education teachers** work in a variety of settings, including family homes, early intervention programs, preschool settings (kindergarten and child care settings) and playgroups.



Special education teachers provide support to families in a range of ways, assisting families to:

- understand more about their child's disability and the impact this may have on learning and development
- establish individual therapy/education program plans
- support the child and staff in the child's participation in local kindergarten and child care programs
- make a successful transition to school.

9. **The audiologist** tests children's hearing to make sure they can hear well enough to learn to speak and understand language. Some children with physical

disabilities, and very young infants, cannot respond consistently to sound. They sometimes cannot show us how much they can hear. Audiologists have special tests to measure the hearing of such children.

If deafness is detected, the audiologist works with the ear specialist to improve the child's hearing. If that is not possible, the audiologist will arrange for hearing aids to be fitted and counsel parents in their use.

All of these professionals may assist families to develop advocacy skills. However, parents may choose their own advocate to accompany them to meetings and appointments to provide support.

What is advocacy?

Some families with a developmentally delayed child feel that they need someone to help them gain access to services or to help them insist on their child's rights. This service is known as advocacy. An advocate works alongside the family, often attending important meetings with them and sometimes speaking on their behalf. Any of the people involved in the care of the child, a friend of the family or a special 'advocate' may be used. Sometimes an advocate can be provided by one of the disability support groups. An advocate also works towards helping the family or the person with a disability develop the skills to speak confidently for themselves.

Current trends in the provision of services

Children with developmental problems benefit from the same activities as other children. Hence a child may attend a local playgroup and then progress on to a local preschool. However, it is important that the child receives the extra assistance that may be required. Specialised services are generally available within the family's local community. Staff may work with children and families at home and later in playgroups, child care centres and kindergartens. It is also recognised that some children may benefit from a specialised program. Specialised programs are provided by a variety of agencies, and may include early intervention programs and preschools. It is important that parents are aware of all available programs.



Which organisations are helpful?

Children with developmental delay can use any of the regular early childhood services such as maternal and child health centres, playgroups, child care centres, family day care and kindergartens.

There are also a large number of organisations, government and non-government, that can help by providing early intervention. Early intervention services may include special education, therapies, family support, parent education, parent to parent contact, and assistance to the child care centre or kindergarten.

The major organisations are:

1. Department of Human Services

Every region has an Early Childhood Team that provides an early intervention service and is able to help families find and use other local services.

Contact the Association for Children with a Disability for information about your local service.

☎ 9818 2000

☎ 1800 654 013 freecall (for rural families)

2. Hospitals

Therapy services may be provided through some hospitals, particularly the Royal Children's Hospital and the Monash Medical Centre, but also through a number of other metropolitan and rural hospitals.

3. The Yooralla Society of Victoria and Scope Victoria

Both provide therapy and educational programs for children, particularly those with physical and multiple disabilities.

For the Yooralla Society of Victoria, contact:

☎ 9359 9366 (Early Intervention Services)

For Scope Victoria, contact:

☎ 9843 3000

4. Association for Children with a Disability

The Association for Children with a Disability is the peak Victorian organisation representing children with a disability and their families. The Association deals with a broad range of issues including education, early intervention, respite, therapy services, aids and equipment, parent support, post school transition issues, home and community care, recreation and palliative care. Most of the members are parents or carers of children with a disability. The Association has also produced a booklet called 'Through the Maze', which is a guide to benefits and services for families of children with a disability. For more information, contact:

☎ 9818 2000

☎ 1800 654 013 freecall (for rural families)

5. Noah's Ark Toy Library and Family Resource

Noah's Ark provides family support, sibling and parent groups, therapies, advice on toys and equipment and recreational programs, as well as other services.

☎ 9529 1466

6. Children's Services Resource and Development Officer

Assists children with additional needs to access long day care, occasional care, family day care, before and after school care and school holiday programs. Contact your local council or the Association for Children with a Disability.

☎ 9818 2000

☎ 1800 654 013 freecall (for rural families)

7. Preschool Field Officer

Provides information, support and advice to parents and preschool staff, assistance in developing individual programs and transition to school. Contact your local council or early childhood service.

8. ADEC

Action on Disability in Ethnic Communities can provide support to families and people with a disability from non-English speaking backgrounds.

☎ 9383 5566

9. Specific Home Help

Local councils through their specific home help or respite care service can provide family assistance and in home care for a child with developmental delay. Local government may also provide limited out of home respite services.

10. Parent Support

This may be provided by consumer organisations such as:

- Association for Children with a Disability (see also description previous page).

☎ 9818 2000

☎ 1800 654 013 freecall (for rural families)



- STAR Victoria – advocating for people with intellectual disabilities and their families.
☎ 9650 2730
- Down Syndrome Association of Victoria
☎ 9486 2377
- Regional Parent Support Programs. Telephone Association for Children with a Disability for further details.
☎ 9818 2000
☎ 1800 654 013 freecall (for rural families)
- Genetic Support Network of Victoria
☎ 8341 6315

11. Early Choices

Early Choices programs provide flexible respite and support packages to families who have a child with a severe disability and high support needs. The child must be under school age. The family may be linked with existing services or funding may be used to buy additional respite or support services.

12. Making a Difference

Making a Difference is a program that provides support for families caring for a child with a disability and with very high support needs. Families may be eligible if they are caring for a child aged between five and eighteen years, with a moderate to severe disability and complex support needs. The program can link families to existing services and provide resources for them to purchase their own support.

13. Linkages

Linkages provides assistance to young people and their carers whose quality of life is being adversely affected by their disability. The family may be linked to existing services or funding may be provided to assist with individual needs.

14. Equipment and Aids

Equipment and aids can be borrowed from local hospitals and the Yooralla equipment library. Funding for purchasing equipment is provided through a State Government program VAEP (Victorian Aids and Equipment Program). Obtain further details from your paediatrician or therapist.

15. Disability Intake And Response Service

Information about local services for people with a disability, their families and their carers. The internet site is www.disability.vic.gov.au
☎ 1800 783 783

16. Financial Assistance

The Commonwealth Department of Social Security provides a carer allowance to families of children with a significant developmental delay. Apply to Centrelink for this.

Preparing for school

Choosing the most appropriate school can take considerable time and planning when your child has developmental delay or a developmental disability.

Parents often ask “Will my child go to a normal school?” There are several options available. All children are entitled to an education through their local primary school. This is called inclusion with the special requirements and resources for the child being made available to the local school. There are also a small number of schools that provide more specialised programs for children with intellectual or other forms of developmental disability. Workers who know your child well, such as your therapist, preschool teacher or paediatrician, will be able to provide information and advocacy for you and your child in preparing to choose a school and equip your child with appropriate supports.

Schools may request assessment reports to establish your child’s needs and your doctor or therapist can also assist in ensuring these are performed and made available to you to provide to the school.

Regional offices of the Department of Education provide information and resources about schooling for children with developmental problems. There are several publications that may be useful for families. ‘Going to School – the Move from Preschool to School for Children with Disabilities’ is published by the Specialist Children’s Services Unit, Victorian Government Department of Human Services and is available through the Association for Children with a Disability. A handbook to assist families of children with disabilities in the school setting is available through regional Department of Education offices and schools. In addition, the STAR Association has a series of booklets about integration which may be helpful for families.

Once at school, the special requirements of your child may be reviewed from time to time with teaching staff and therapists involved in your child’s development. One such time to do this is at the beginning of each school year, when a new teacher is being made aware of the particular needs of each student in their grade.

Will my child be able to obtain a job and will my child be able to live independently? In the early years of life, it is often impossible to answer these questions. It is important to remain optimistic about your child's progress, yet realistic when the problems are severe. This is often a difficult balance to achieve.

However, all children continue to learn and as adults they will also continue to develop new skills. Each new skill contributes to the growing person's scope for pleasurable activity and participation in society.

Notes:

