Welcome to Little People of Ontario!

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A Letter to New Parents

Dear New Parents,

Congratulations on your new addition to the family! Whether you found out before giving birth, or after the fact, the doctor's news most likely came as a shock. This is where your journey begins. How you handle the news and every day after is what makes the journey your own. This word, "dwarfism," may not fit with the visions you had for your child's future – perhaps you feel upset, angry, scared, worried, or you fear judgment and ridicule. If needed, grieve the baby you'd been imagining in your mind. It will take some time, but you'll figure out soon enough that raising a child with dwarfism isn't what you imagined it to be. It will be a journey for your entire family, one that may cause you to change your perceptions and open your minds. It can be extremely rewarding in ways you hadn't envisioned possible.

You may have many questions buzzing around in your head. It can be overwhelming at first to see the volume of unfamiliar information out there, and not know where to start. There seems to be an endless amount of advice in books, on the internet, and from other people. If both parents are average height (as is usually the case), dwarfism probably wasn't even on your radar before. You might feel like you're going through this alone. Little People of Ontario was founded for this purpose. We want to be there for the important moments of you and your child's lives, from birth onwards. The information we can provide you, and the support from our great network of members, can and will help you and your child navigate this journey.

A big part of the process is accepting that you have a short-statured child in an average-height world. You will need to become a strong advocate for your child as he or she grows up and faces the challenges of a world made for a different size. Educating yourself so you can support your child and educate others is key. We hope that this guide, along with the other resources the organization and its members can provide, will have you well on your way to successfully navigating the wonderful journey of parenting a short-stature child!

We are so glad you could join us,

Little People of Ontario

Who We Are

Little People of Ontario (LPO) is a provincial, charitable organization that provides life-long fellowship, support, and information to people of short stature, their families, and friends.

Started in 1965, and operated entirely by volunteers, the LPO has been raising awareness and educating the general public about dwarfism, showing them that little people are unique, capable, and incredible in every way.

Allan Redford, the President of LPO, leads a dedicated group of little people and their allies in achieving these goals. Together, the members of this organization hope to help Ontario become an accepting place for people with dwarfism.

What We Do

For over 50 years, LPO has provided up-to-date information about medical issues, community and government support services, and ongoing education about the challenges of living life as a little person (LP). Members can access numerous resources through the LPO website and receive regular newsletters. The LPO also brings the LP community together and raises awareness in the public eye by hosting social activities and collaborating with other groups, such as the Toronto Waterfront Marathon.

Through peer support and personal example, our members are supportive of all those who reach out to LPO by providing medical, environmental, educational, vocational, and parental guidance. This is facilitated through general introductions, parent meetings, and the Facebook group.

Introduction

This guide for new parents provides accurate information about various aspects of dwarfism. LPO is aware that every parent has a different perspective on raising a child with dwarfism, and we have kept this in mind when creating this guide. We hope that you use this information to better understand your child's situation and become more confident in your role as a parent and advocate. Your own experiences and perceptions will play a role in defining who you are as a parent, and what you can do for your child.

Dwarfism – What Does It Mean?

Dwarfism is a medical condition that results in an adult height of 4'10" or less. While the average height of an adult with dwarfism is 4' tall, heights can vary from 2'8" to 4'10". There are over 400 different types of genetic disorders affecting bones and joints, which collectively are called *skeletal dysplasias*. Many of these disorders lead to dwarfism, of which the most common is achondroplasia. Although most types of dwarfism have a genetic cause, they may not be inherited in the family. In many cases, both parents of a child with dwarfism are of average height. Dwarfism is most commonly caused by a genetic change in a gene important for bone growth (Zhou, 2021). The genetic change may be inherited from a parent with dwarfism or it may be new in the child (i.e. *de novo*). Dwarfism can be categorized into two main groups: disproportionate dwarfism and proportionate dwarfism.

1. Disproportionate dwarfism is more common than proportionate dwarfism. It is a type of skeletal dysplasia that affects certain parts of the body more than others. The most common type is achondroplasia, where the trunk size is average-size and the limbs are shorter than average.

2. Proportionate dwarfism occurs when someone's entire body is affected. The entire body is smaller than average, but their limbs, trunk, and head are all proportional to each other. While some forms of proportionate dwarfism are skeletal in nature, others are caused by hormonal or metabolic disorders, such as growth hormone deficiency (Zhou, 2021).

Most people with dwarfism experience some medical complications over their lifetime. Potential interventions may include surgeries to straighten bowed legs during active growth (also called guided growth) or corrective spinal surgery to relieve pressure on the spine (spinal stenosis). While the possibility of invasive surgery may be frightening, surgeries are only considered after careful assessment and discussion with the surgeon. People with dwarfism generally have normal lifespans, health, and intelligence—barring a few very rare forms.

While there are some activities that children with dwarfism should be cautious of (i.e., contact sports), children should be encouraged to play with their peers, participate in school activities, and have a regular childhood. Many adults with dwarfism report that they lead fairly ordinary lives in an average-height world, apart from a few well-placed stools and pedal extenders for their cars.

Genetics of Dwarfism

Achondroplasia is the most common type of dwarfism. It is caused by a specific pathogenic variant (mutation) in the Fibroblast Growth Factor Receptor 3 (FGFR3) gene (see Table 1). The FGFR3 gene plays an important role in regulating bone growth and maintaining bone tissue. Every person has two copies of the FGFR3 gene, one inherited from each parent. Achondroplasia is an autosomal dominant condition which means that a single pathogenic variant in one copy of the FGFR3 gene leads to the condition. Even though autosomal dominant conditions are genetic, they are not necessarily inherited.

Disorder	FGFR3 Gene Pathogenic Variant
Achondroplasia	c.1138G>A (p.Gly380Arg) c.1138G>C (p.Gly380Arg) c.1123G>T (p.Gly375Cys)
Hypochondroplasia	c.1620C>A (p.Asn540Lys) c.1620C>G (p.Asn540Lys) c.1619A>C (p.Asn540Thr) c.1612A>G (p.Ile538Val)
Thanatophoric dysplasia	c.742C>T(p.Arg248Cys) c.1111A>T(p.Ser371Cys) c.2419T>A (p.X807Argext141) c.2421A>T (p.X807Cysext141) c.746C>G(p.Ser249Cys) c.1118A>G(p.Tyr373Cys) c.2420G>T (p.X807Leuext141) c.2421A>C (p.X807Cysext141) c.1108G>T(p.Gly370Cys) c.2419T>G (p.X807Glyext141) c.2420G>C (p.X807Serext141) c.2421A>G(p.X807Trpext141)
SADDAN	p.Lys650Met

Table 1. Skeletal dysplasia is caused by pathogenic variants in the FGFR3 gene.

About 80% of people with achondroplasia are born to average-height parents. In this situation, achondroplasia does not occur due to the gene being “passed down” in the family, but rather due to a new pathogenic variant in the FGFR3 gene in either the sperm or the egg that gave rise to the child. The chance that these parents would have another child with achondroplasia is low (<1%). However, it is impossible to determine if other egg or sperm cells will have the pathogenic variant in FGFR3. This is known as gonadal mosaicism.

When one parent has achondroplasia, there is a 50% chance of the child inheriting achondroplasia in each pregnancy and a 50% chance the child will be of average height (Figure 1).

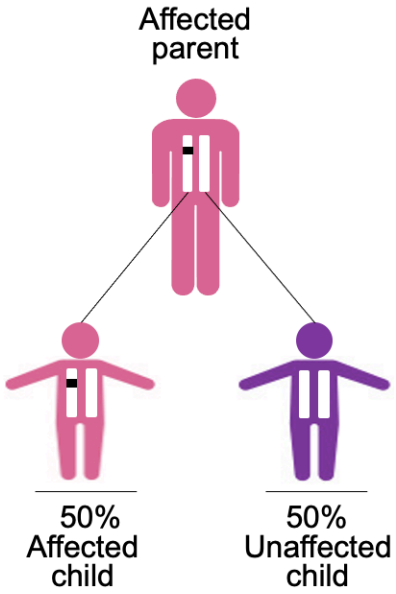

Figure 1. One parent has achondroplasia, resulting in a 50% chance that the child will inherit achondroplasia

When both parents have achondroplasia, there is a 50% chance the child will be born with achondroplasia, a 25% chance the child will be average height, and a 25% chance the child will inherit the pathogenic variant from both parents (Figure 2). Unfortunately, the inheritance of both pathogenic variants leads to death at birth or shortly after birth (Pauli & Legare, 2018). Specific pathogenic variants within the FGFR3 gene can lead to other types of dwarfism such as hypochondroplasia, thanatophoric dysplasia, or SADDAN syndrome. Other skeletal dysplasias with dwarfism such as diastrophic dysplasia, spondyloepiphyseal dysplasia, pseudo-achondroplasia, and osteogenesis imperfecta are caused by pathogenic variants in other genes. While most skeletal dysplasias are autosomal dominant, some are inherited in an autosomal recessive manner. In autosomal recessive skeletal dysplasias, each average-height parent unknowingly carries one pathogenic variant which is then passed to the child. In each pregnancy, there is a 25% chance of both parents passing on the pathogenic variant leading to the condition, and a 75% chance that the child with have one or no copies of the pathogenic variant (Figure 2).

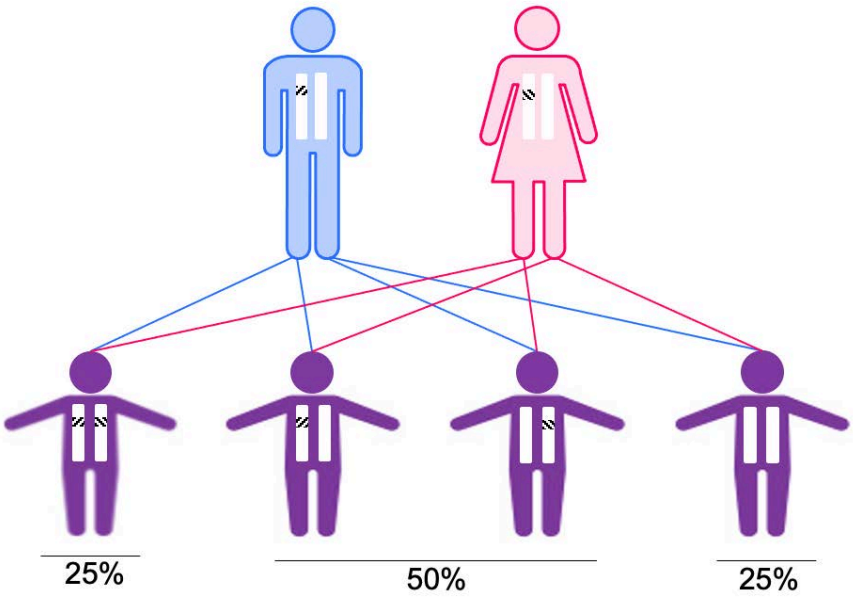

Figure 2. If both parents have achondroplasia, the child has a 50% chance of having achondroplasia, a 25% chance of being average height, and a 25% chance of inheriting both pathogenic variants. Similarly, in autosomal recessive skeletal dysplasias, each average-height parent unknowingly carries one pathogenic variant. In this case, the child has a 25% chance of having the condition, and a 75% chance of having one or no copies of the variant.

Previously, there were no treatments available for skeletal dysplasia due to its genetic causes. Skeletal dysplasia has no hormonal or metabolic causes and therefore cannot be treated with hormone therapy with the exception of osteogenesis imperfecta which can be treated with bisphosphonates to reduce the risk of fractures. Currently, there is a new clinical drug trial underway testing the effectiveness of vosoritide, an analog of C-type Natriuretic Peptide (CNP), for children with achondroplasia. As of summer 2018, BioMarin (Biomarin Pharmaceutical Inc.) has been conducting a randomized, placebo-controlled study of vosoritide over a year-long period in 70 children under the age of 5. In September 2021, Biomarin applied to the FDA for approval of the use of vosoritide. Other pharmaceutical companies are looking at different approaches for the treatment of achondroplasia.

A Child's Differences and Similarities

When Will People Notice My Child is Different?

Many parents worry about the point in time when their child begins to look noticeably different from children their age. It may be helpful to tell your family and friends when you find out – this may save a lot of confusion and explanation down the road -- but first, take the time to register your feelings. As difficult as the initial whirlwind of emotions may be, your attitude going forward will affect how others perceive your child.

Explaining dwarfism and its implications to the people around you in a simple and informative manner, while maintaining a positive outlook, will often help them better adjust to the news. We recognize that this may be more challenging in some families based on cultural beliefs. Raising a child with dwarfism in a supportive and understanding environment that you helped foster will help your child become happy and independent.

How you approach disclosing personal information to people outside of your immediate circle may vary. Some people are very supportive of visible differences between individuals. However, discrimination remains widespread in our society and you will likely encounter some difficult times in the journey ahead. When your child is only a few months old, most people will not notice a difference. As your child gets older, casual acquaintances or strangers may be confused when you tell them how old your child is because of their size. It is completely up to you to decide what and how much you say.

Each family is different and you may answer differently depending on the situation. You are not responsible for educating the world about dwarfism – just the people in your child's world. As your child starts walking and talking, people may be naturally curious. By this time, you'll have several strategies to deal with these situations. Keep in mind, dwarfism is rare, and the public is not very educated about the condition and uses appropriate terminology. You may hear hurtful words and disparaging comments about your child. In addition, prevailing assumptions publicized by popular culture and myths can be annoying, but a simple explanation could serve to educate those around you and diffuse the situation.

Speaking with someone who has been through similar experiences and understands what you're dealing with can be helpful and revive positivity. With time, you may develop quick and concise responses to questions others have about your child. Consider thinking of this process as an opportunity to educate others about a little-known topic and make society more accepting as a result!

Will My Child Have Fewer Options in the Future?

This certainly doesn't have to be the case! Little people can do everything average-height people can with only a few exceptions. They can live fulfilling lives and become contributing members of society. There may be rough patches in their lives in which a typical life seems unattainable. Having a positive role model with dwarfism can help normalize these feelings and provide a source of encouragement. There are many people who are short-statured that become lawyers, musicians, accountants, engineers, and more. With positive role models and a belief that they can achieve what they put their mind to, they can achieve their goals and aspirations.

Does This Condition Affect My Child's Quality of Life?

This depends on many factors, including your child's type of dwarfism and if any complications occur. First of all, the psychosocial effect associated with being "different" may pose a concern. Bullying at school, discrimination, feelings of loneliness, and stress may have a negative impact on personal well-being and how your child interacts with the world. This is discussed at length in the following section. Secondly, medical complications that lead to many hospital visits and/or surgeries may impact their quality of life. While many little people have an average lifespan, certain factors, such as their propensity to weight gain, could affect their lifespan. This is why understanding your child's condition and potential complications is important – the better you understand it, the better you may be able to reduce the risk of complications.

Will My Child Have Learning Difficulties?

Most types of dwarfism do not affect a person's intellectual abilities or cause personality disorders. This is especially important to keep in mind when your child begins school. Be explicit and clear when explaining how dwarfism affects your child; especially If you choose to inform other parents at your child's school, and during the development of an individualized education plan (IEP) (both discussed later on). Often the only school accommodations required are physical changes that allow them to complete the activities offered to their average-height peers. According to Statistics Canada, about 3.2% of Canadian children have a **learning disability**. We expect the same rates for LPs.

Emotional and Social Health

It is important to teach your child about their dwarfism at an early age. The most well-adjusted and psychologically healthy children with dwarfism are those who understand their differences from a young age. For very young children, this explanation can be as simple as, "Your bones don't grow as fast as other kids, so you're going to be smaller than other kids your age." As children get older, they can understand more information about their specific kind of dwarfism. Holland-Bloorview Rehabilitation Center has a useful guide for parents of children with disabilities, explaining how to navigate transitions and developmental milestones, which can be accessed at https://hollandbloorview.ca/services/programs-services/timetable-growing.

Children with dwarfism who grow up in a loving, optimistic household and learn from an early age that there is nothing "wrong" with them—just different—have better self-esteem, confidence, and social skills than children who do not have a supportive home life. Children are very perceptive and pick up on negative attitudes and interactions more than we realize.

Placing low-hanging mirrors around the house so your child can see themselves is one way parents can help their child build a positive self-image. Reading books to your child from an early age that explain dwarfism and difference can also have a valuable impact on children's self-image. For older children, role models with dwarfism can further help to foster a positive sense of identity. LPO has included a list of age-appropriate reading and viewing materials for parents and children at the end of this guide.

Many parents have espoused the benefits of having their child connect with other LPs their age and have positive adult role models. LPO is a great resource for meeting other LPs in your area and for your child to make new LP friends. It is also a way for you as parents to connect with other parents of LPs. For average height siblings, being exposed to the dwarfism community can help them connect with their short-statured siblings

It is also important to treat and dress your child age-appropriately. While it may be convenient to carry your child instead of having them walk, you should treat your child the same as any average-height child the same age; that means the same expectations (i.e., dressing, feeding, chores, and toileting). While some accommodations and adaptations are unavoidable, parents should take every measure to foster their child's independence as much as possible, even if it means some tasks will take a bit longer. For clothing, it is a struggle to find age-appropriate clothes and patterns. If you wouldn't dress an average-height 8-year-old in a t-shirt with balloons and clouds, you shouldn't dress a short-statured 8-year-old in it either. While altering average height clothing to fit an LP child may be more time-consuming and expensive than simply buying clothes that fit, it is important for your child's self-esteem that they feel their age.

We live in a society where it can be very hard to be visibly different. Socially accepted beliefs that equate tallness with success can be discouraging for people with dwarfism and their families. It is important that you emphasize the contrary to your child: size is no measure of power, success, or intelligence. Combat language that employs negative stereotypes or images of short-statured people (e.g. "puny", "pint-sized", "coming up short", etc.) by stressing character over appearance.

Medical Considerations

Your Child's Medical Needs

"Will my child be healthy?" "Will they need surgery?" "Will they have to use a wheelchair?"

These are just some of the questions that may run through a parent's mind when they find out their child has dwarfism. This can be a frightening time with many questions and uncertainties. There are countless articles, websites, and forums providing medical advice, considerations, and information on dwarfism. Sorting through massive amounts

of information can be very overwhelming, especially when dwarfism and its implications may be new to you.

Fortunately, many other parents have already been through this process and are often the most helpful allies in trying to find the best care for your child. Joining the LPO Facebook group can be a great way to connect with other parents of LPs and share advice and recommendations on healthcare providers experienced with LPs in Ontario.

Doctor visits a child with dwarfism and his mother.

Apart from joining the Facebook group, parents of a newly born LP baby can also call their Local Health Integration (LHIN) (previously called CCAC) first as they may be a useful starting point in finding information on services and referrals to health professionals. Some regions also employ infant development workers, who may be able to connect you with resources and provide free counselling for parents. We have included a list of recommended Ontario medical personnel and facilities in the resources section of this guide.

Disclaimer: Any medical advice LPO provides in this guide is merely a guideline and not intended to replace the advice of a medical professional. Please consult your primary doctor as each child is unique even if they may share the same diagnosis.

Articles on several dwarfism diagnoses can be found on the LPO website at the following link:

littlepeopleofontario.com/index.php?rt=product/category&path=68_72

lpamrs.memberclicks.net/index.php?option=com_content&view=article&id=66

Participation in physical activity and sports can help to build muscle, flexibility, and cardiovascular endurance in LPs, as well as a sense of confidence and positive self-image. There are several sports organizations dedicated to providing access to sports and recreation for people with dwarfism. The **Dwarf Athletic Association of Canada (DAAC)** and the **Dwarf Athletic Association of America (DAAA)** are two of the biggest in North America. In Ontario, LPO has a summer camp that children with dwarfism can participate in, as well as a sporting event at the spring LPO conference. Every 4 years, the World Dwarf Games are held; this event is similar to the Paralympics and brings together little people from around the world to compete in sporting events.

Practical Considerations

When the World is made for Average Height

Little people face some practical issues in life, but with a little support and creativity, they can do many of the same things as their average-height friends and family. The best place to get information is from little people or the parents of little people, who already have experience. In this section, we have addressed some common questions about general areas of life. More specific references can be found at the bottom of this document.

Adaptations in Your Home:

There are differing views on the number of adaptations that should be made to a home. While some families make many adaptations to ensure everything is easily accessible for the child, others opt to make few changes because their child has to live in an average height world. Regardless of preference, items such as light switch extenders (or lowering the switch so that they can be reached), doorknob extenders, stools, potty chairs, adaptive furniture (including desks and chairs), and more can be useful. Your child may not need all these things, or they may use them at only one stage in their life. The main goal for parents should be to maximize the child's independence. For a full list of adaptive equipment, check out the *Adaptive Equipment Guide* on LPO's website.

Clothing:
While your child is still an infant, clothing isn't typically an issue. You can shop for clothes at regular stores and focus on finding pieces that have a good cut and style. However, finding age-appropriate clothing for your child as they age becomes more difficult. Nonetheless, there are several stores that stock clothing in small sizes where you can often find something that fits your child. Sometimes alterations need to be made, either by a tailor or yourself. There is even a fashion designer, Kathy D. Woods, who designs fashions made specifically for adult women with dwarfism. Specialty stores that tailor-make clothing also exists, but these are harder to come by and are usually for teens or adults.

Toileting:

Potty training your short stature child often presents unique challenges. Nonetheless, there are ways for children with dwarfism to use the bathroom at home with comfort. At first, it may be easier to use a potty chair rather than a standard toilet. Your child will need to learn how to maneuver their pants up and down – they may need a mat for the floor or an adaptive device. To reach the toilet seat and sink, a step stool or built steps can be helpful. Depending on your child's condition, wiping may take practice and require a special method. One option is to dedicate an extra bathroom to your child.

Another option is to re-do the main bathroom to create a more accessible environment. Every parent of a little person has been through this, so reach out to other members of LPO for more suggestions.

Books on Dwarfism:

It can be difficult to find medical books on human dwarfism in public libraries. You can find information online (see below) or from your child's doctor. However, there are children's books on dwarfism which can be invaluable resources. Books such as *I'm Just Small, That's All* (ages 3-9), *Not So Tall for Six* (ages 4-8), and *Freak the Mighty* (ages 8-12) are popular picks. Not only do these books help your child normalize their condition, but they can also be used by teachers at school to raise awareness in other kids. There are also a few novels written from the perspective of little people, such as *The Lives of Dwarfs* and *Stones from the River*.

Dwarfism Information Online:

The internet has a wealth of information about people with dwarfism. This can include medical information and doctor lists, schooling advice, adapted clothing and furniture lists, and more. Both formal and informal (blogs, forums) sources can provide you with the information you need to raise your child. LPO has a wide range of resources available on the website and can also connect you with information through email newsletters and Facebook groups. Little People of America (LPA) is also a large organization for people with dwarfism that's worth checking out.

Help from Government Programs:

Some forms of dwarfism can be more debilitating than others. Even though most people with dwarfism do not consider their condition a disability, your child may qualify according to the province of Ontario. Even if you prefer not to define your child as "disabled", taking advantage of government programs and services may be beneficial. This aid may include physical/occupational therapy, equal opportunity laws (AODA), college grants and loans, accessible parking permits, early intervention programs and income support. Funding for medical care (e.g. drugs not covered by the Ontario Drug Benefit), funding for adaptive equipment, and in-school adaptations (IEP) are other benefits. The Canadian and Ontario Government websites outline a wide range of these services. Contacting the Ministry of Community and Social Services, school district Special Education staff, and hospital are also good places to find out more.

<u>Ontario Disability Support Program (ODSP)</u>

ODSP is Ontario's main provider of financial support for people with disabilities. To qualify for ODSP, you need to be at least 18 years old, a resident of Ontario, demonstrate financial need, and meet the definitions of a person with a disability.

Assistive Device Program (ADP)

ADP is another government program that provides financial assistance to Ontarians with long-term disabilities who require assistive devices.

Child Disability Benefit

The Child Disability Benefit is an income benefit for low-moderate income families with children under 18 who have a disability. A supplement to the Canada Child Tax Benefits, it can pay up to $2,000 a year for eligible families.

Disability Tax Credit (DTC)

Provincial Sales Tax Rebate for Vehicles

The Provincial Sales Tax Rebate is a tax rebate on vehicle modifications and vehicles used to transport children with disabilities. Parents can call the Ministry of Finance Retail Sales Tax Branch for more information.

Help from Non-Government Programs:

Several organizations provide financial assistance to families of children with disabilities when ODSP and ADP allowances are not enough. Some of these programs require demonstrated financial need.

March of Dimes

March of Dimes Canada has an assistive device program (ADP) that provides financial support to adults with disabilities who need assistive devices to increase their mobility and independence.

These programs include a Home and Vehicle Modification Program (HVMP) which provides financial assistance to people with disabilities who need modifications to their cars or homes. This program can provide up to $15,000 for home modifications over the course of a lifetime, and up to $15,000 for vehicle modifications every 10 years.

Easter Seals Canada

Easter Seals Canada offers services for children with disabilities up to age 19 who use assistive devices such as walkers, wheelchairs, and scooters for mobility. This includes funding programs for assistive devices such as lifts, ramps, bathroom aids, power chairs, specialized strollers, and orthotic devices; up to $3,000 a year per child. Easter Seals also has camp programs for children with physical disabilities with financial

assistance available. Their website is a good resource for finding out about different financial assistance available for parents and families of children with disabilities.

For the Love of a Child

This organization provides financial assistance to families in the Durham region who have a child with a disability to help families afford adaptive equipment or mobility devices, camps, or therapy for their child.

Jennifer Ashleigh Children's Charity

This charity provides funding for children with disabilities whose household income is less than $65,000 who have already exhausted all other available sources of financial aid, including government funding and non-profit funding.

Driving:

Getting your driver's license is a big step for any teenager, but for little people, it can pose some unique problems. The first thing to consider is the car. Depending on the specific type of dwarfism, many little people have an average-sized trunk, so the steering wheel is at a difficult distance and angle to access. Finding a car that works for your child will require some trial and error. Since LPs are sitting much closer to the steering wheel, they are very close to the airbag, and it is recommended that drivers/passengers be at least 1 foot away. Talk to your doctor about this issue. Another major consideration for vehicle modification is the pedal extender. You can get a permanent or temporary extender, but you need to make sure the foot is not dangling. Check with your insurance company to see what level of modification can be made to the vehicle.

During the required eye test for a G1, your child may need a stool to be level with the apparatus. Temporary pedal extenders can be used during training and the G2 test. Remember that testing centers must accommodate under the Ontario Human Rights Code. When it comes to driving lessons, many LPO parents have found Young Drivers of Canada to be the most accommodating, but also the most expensive. Another option is going to your independent or local driving school, many of these offer insurance discounts.

Attending School

Getting Acquainted

School is a subject that parents face a lot of uncertainty with. Navigating the Ontario school system with a child with special needs can seem like a daunting task. However,

most schools are cooperative in adapting to the environment so that your child can maintain independence and minimize physical stress.

If your child has dwarfism, the Ministry of Education will likely consider them to be an "exceptional" pupil due to a physical disability. Ontario's Education Act requires that school boards provide or purchase from another board special education programs and services for their exceptional pupils. This means that whatever school district you're in, schools should make accommodations for your child!

The most important thing to remember when planning for your child's transition to school is to begin the process months in advance. A good way to start is by attending LPO meetings to talk to other parents about their experiences with schooling. It may also be helpful to contact the Special Needs Director/Coordinator for your district for more information. Once you've gathered some information and knowledge, you can begin searching for the right school and ensuring a plan is in place for your child's arrival. We have outlined below a list of recommended steps to prepare yourself and your child for entry into school.

School Prep Checklist

- ☐ Obtain a medical diagnosis and find OT/PT/caseworker
- ☐ Join LPO and attend meetings to speak with more experienced parents
- ☐ Contact your school district's Special Education Coordinator/Director
- ☐ Tour potential schools with your child
- ☐ Request an Identification, Placement, and Review Committee (IPRC) meeting from the future principal of the chosen school
- ☐ IPRC meeting is held, and your child is deemed exceptional; Educational Assistant potentially hired by the board
- ☐ IEP is created by the principal with your help
- ☐ Child receives everything he/she needs while at school
- ☐ The situation is reviewed annually unless you deem it unnecessary

Choosing a School:

Some schools may already have accommodations in place for LP students or other students with physical disabilities. In this case, it may be best for your child to attend this school because staff are familiar with the condition and the environment has already been adapted for their needs. Many LP parents take tours of potential schools with their child first – this allows you to see whether or not the school is suitable, and what kinds of accommodations (if any) will be needed. If there is no school in your district that you feel can support your child, you are welcome to choose one in another district.

The Identification, Placement and Review Committee (IPRC):

Regulation 181/98 requires that all school boards set up an Identification, Placement and Review Committee (IPRC). It is composed of at least three persons, one of whom must be a principal or supervisory officer of the board. The IPRC will do the following:

- Decide whether or not your child should be identified as exceptional;
- Identify the areas of your child's exceptionality;
- Decide an appropriate placement for your child; and
- Review the identification and placement at least once in each school year.

To start an IPRC for your child, you must write to the chosen school's principal and request a referral. The principal must send you written notification within 15 days of making the referral, which will include an approximate date for the meeting and a parent's guide. The principal may also ask you for permission to obtain a psychological or health assessment of your child. While an educational assessment will also be performed, parental permission is not required for this. At least 10 school days before the IPRC is set to meet, you (and your child, if 16 or over) will receive written notice of the meeting and an invitation to attend; you must indicate if you can attend. Before the meeting, you will also receive a copy of all information that the chair of the IPRC has received. If you can't attend on the given date, contact the principal to arrange an alternative date or let them know you will not attend. You and your child's principal can request for others to attend the meeting, including an advocate to speak on your behalf.

You will receive a written statement of the IPRC's decision, and if you didn't attend the meeting, it will be mailed to you. You will be asked to sign this document to indicate that you agree with the IPRC's decisions and recommendations. If you attended the meeting, you may be asked to sign at that time. Note, however, you have 30 days to return the signed document to the IPRC. Once the document is signed and returned, the board will notify the principal, who will then begin the process of developing your child's Individual Education Plan (IEP).

If you disagree with the IPRC's decision, you have 15 school days to request a second meeting of the IPRC. If you are still unhappy after this, you have 15 school days from the second decision to file an appeal. Your request for an appeal must be made in writing to the secretary of the school board. You must indicate the decision(s) with which you disagree and your reasons for disagreeing. Note that if you disagree with the original decision but do not request a second meeting or file an appeal, the decision of the IPRC will automatically be implemented after 30 school days.

A review IPRC meeting will be held each year, during which your child's progress may be reviewed and the education plan revised. This review may be waived with your written permission, but it is recommended that you do not waive it. The annual IPRC is your chance to help ensure that your child begins each new school year in the most appropriate environment possible. Once your child has been in a special education program for 3 months, you may also request a review of IPRC any time.

The Individual Education Plan (IEP):

If the IPRC has deemed your child exceptional, the principal of the school is required to create an IEP (Individual Education Plan) for your child. The Ministry of Education defines an IEP as “a working document which describes the strengths and needs of an individual exceptional pupil, the special education program and services established to meet that pupil’s needs, and how the program and services will be delivered. It also describes the student’s progress.” The way IEPs are used can differ by the school board or by the schools within one board; make sure you are clear on what applies to your situation.

The process of developing an IEP will involve you, your child, school staff, and other agencies as necessary. If your child has an occupational therapist and/or physical therapist, they can help facilitate the process by recommending equipment, support, and modifications. These professionals can complete various assessments to ensure they offer you and the school an informed decision. Remember, your child will have a lot to say about themselves, their strengths, their needs, their interests and preferences, and what they would like to do in the future. It can be helpful to include them in their IEP meeting when appropriate.

After the IEP’s initial development, your child will be assessed every year. The assessment will involve the necessary agencies mentioned above, and any more deemed appropriate, to ensure the support provided is sufficient. You may want to consider including teachers; they spend a great deal of time with your child in class and could have important input. All parties can be invited by the school to attend the meeting.

If you do not believe your child needs an IEP that is up to your family to decide. However, please note that if an IPRC has decided, per your request, that the child is exceptional, an IEP *must* be created. Keep in mind that school staff can’t be experts on every type of exceptionality. Therefore, it is recommended to have an IEP, even if not all the accommodations outlined are being actively used. These can always be revised at annual review meetings!

Schools of Thought on Accommodations:

LP parents have unique experiences with the school. As a result, there are generally two schools of thought when it comes to providing accommodations in school. The first is the idea that it is best to provide as many accommodations as possible; everything that *can* be accommodated *should* be accommodated. The second is that providing as few accommodations as possible will allow the child to learn how to function in a world that is built for average-height people; accommodations should be provided only when *necessary*. It is up to you and your child to decide where you fall on this spectrum.

Accommodations:

Deciding your philosophy on accommodations will help determine what you think will be necessary for the IEP, and supplementary additions. A very detailed list of possible accommodations can be found in our Best Practices Policy on the LPO website, which outlines what schools might want to put in your child's IEP. However, there will be certain things that parents will provide rather than the school. Per your wishes, they may include:

- Hand sanitizer in child's backpack to save washing hands in the sink
- Water bottle in child's backpack to be refilled by buddy or teacher rather than use the water fountain
- Prescription and non-prescription pain relievers to be left at school
- Bento boxes with side clasps for lunch rather than Ziploc bags
- Electric scooter to get to school if preferred over bus
- Homemade portable seatbelt (webbing and D-rings) to keep in backpack for field trips or if the regular bus breaks down
- Homemade cushion to fill in space between child's back and seat

Parents can also take charge in other ways depending on the level of involvement you and your child are comfortable with. If you would like to raise awareness in the school, this can be done in many ways. Some may wish to leave a fact sheet with teachers so that they understand the condition and preferred accommodations. Many have chosen to send a letter home with students that outline the condition for other parents and their children, leaving an open forum for questions. A sample letter for this purpose can be found at the bottom of the schooling section. The principal can hold an awareness assembly for the entire school or grade or class, which can also involve the parents. LPO provides resources for these presentations on our website. Teachers can become involved in a classroom setting by having smaller presentations, reading special children's books, and promoting general inclusiveness.

No matter what you choose to do, maintaining open and honest communication between you, your child, and the school staff will make the whole process much easier. Remember, you are your child's best advocate!

Sample Take-Home Letter/Email: (See the following page.)

Dear Parents,

You may be familiar with our *son/daughter* **(Child's name)** from attending **(old school name if applicable)** last year, but for the new parents, she will be attending **(new school name)** with your child this school year. We are writing this letter because **(Child's name)** has **(condition name)**, a form of dwarfism, and we have found it is quite common for both children and adults to have questions about *his/her* condition. Even though your child may be older or younger than **(Child's name)**, they may meet on the playground or at another school event. Friends have found it helpful to have the correct information.

The following are a few basic facts about dwarfism:

- There are over 400 distinct types of dwarfism. **(Child's name)** has **(condition name)**, **(brief overview of condition)**.
- Some dwarfism types are recessive (carried within the parents' genes) and others are what is called "spontaneous mutations at conception" – **(Child's name)**'s form *is/is not* recessive. In other words, (did someone carry the gene? Or was it a genetic mutation?)
- Over 80% of all people with dwarfism have average-height parents and siblings, *as is/though this is not* our case.
- There are no "cures" for dwarfism.
- **(Child's name)**'s adult height is estimated to be **(number)** feet tall.
- Terminology: the word "midget" is not used anymore in the short-stature community; it is seen as a derogatory, slang word. We use the terms "short-stature", "little person" or "having dwarfism" in our home. The word "dwarf" is technically correct although we rarely use it when speaking about a person. Simply using *his/her name* **"(Child's name)"** is preferred.
- We also use "average-height" as opposed to "normal-height". Everyone has their own opinion, but to us, people with dwarfism are just shaped differently, not "abnormal". **(Child's name)**'s learning, playing and motor skills are just like every average child *his/her* age.

We hope a little information will allow you to be able to accurately answer any questions your child may have. Should you have any further questions please do not hesitate to contact us.

We are looking forward to this year at **(new school's name)**. Thank you in advance for your support.

Regards,

(Parent/guardian names)
(Phone number)
(Email)

Conclusion

This guide contains a lot of condensed information which will require time to go over and fully digest. We hope that this guide serves as a base for your inquiries. Our resources section can also help direct you to more information. As you can see, having a child that is "different" just means you need to be willing to adjust your habits and routines. With time, these adjustments will become second nature, and one day you'll be advising new parents who are in the same position you're in now! With time and a shift in perspective we hope you will be able to see just how special a child with dwarfism can be. At the end of the day, every child is unique, and this is something to be celebrated.

RESOURCES FOR PARENTS

BOOKS

For Parents

Dwarfism: Medical and Psychosocial Aspects of Profound Short Stature
By Betty M. Andelson (2011, 368 pages)

- Book on dwarfism research written by the parent of a child with dwarfism. Although it is a medical text, it uses language that is less clinical and more layman's terms.

The Lives of Dwarfs: Their Journey from Public Curiosity Toward Social Liberation
By Betty M. Andelson (2005, 431 pages)

- This book explores the history of how people with dwarfism have been treated and their place in society, dwarfism research, and the recent disability justice movement as it relates to dwarfism. Written by the parent of a child with dwarfism.

Far from the Tree
By Andrew Soloman (2013, 976 pages)

- Widely renowned parenting book for children with exceptionalities. There is a chapter dedicated to dwarfism. The author interviews several parents of children with dwarfism.

Little People – Through my Daughter's Eyes
By Dan Kennedy (2003, 288 pages)

- Kennedy explores the history and culture of dwarfism, medical screening procedures, and his own experiences as the father of a child with dwarfism.

For LP Kids & Their Siblings

Children (4 - 10)

We are Giants
By Amber Lee Dodd (2016, 320 pages)

- A children's novel where the protagonist's mother has dwarfism, and her daughter is of average height.

Even Though I'm Small
By Karen Kelley Smith (24 pages, 2015)

- A picture book about Allie, a little girl with dwarfism.

Stand Tall, Molly Lou Melon
By David Catrow (2001, 32 pages)

- First Grader Molly Melon is "just taller than her dog" with "a voice that brings to mind a bullfrog being squeezed by a boa constrictor", but is fearless, confident, and brave, thanks to her grandma. However, a move to a new school, with a new bully, may pose a challenge to Molly's previously unflappable self-esteem.

Not Too Big… Not Too Small…Just Right For Me
By Jimmy and Darlene Korpai (2014, 36 pages)

- Written for the project Understanding Dwarfism, this picture book answers some of kids' most common questions about dwarfism and explains the condition in a simple, kid-friendly way.

Trudi & Pia
By Ursula Hegi (2003, 40 pages)

- Trudi, a little person, learns to accept that what makes her different is what makes her special when she meets Pia, a brave and fearless lion tamer who also has dwarfism.

Youth (10 - 14)

The Heights, the Depths, and Everything in Between
By Sally Nemeth (2008, 272 pages)

- Set in the 1970s, Best friends Lucy and Jake, a girl with gigantism and a boy with dwarfism, are starting middle school.

Little Klein
By Anne Ylvisaker (2009, 192 pages)

- Harry, known to his small town as “Little Klein, is teased mercilessly by his big brothers but finds companionship in a stray dog.

The Thing About Georgie
By Lisa Graff (2007, 224 pages)

- A novel about a boy in the 4th grade with dwarfism. Each chapter in the book is preceded by a diary entry that asks readers to do a task that Georgie cannot, e.g. touch our toes. This raises awareness of the challenges people like Georgie face in their everyday lives.

Freak the Mighty
By Rodman Philbrick (1993, 160 pages)

- A novel about childhood friends Freak, a genius with dwarfism, and Max, who has a learning disability.

<u>High School (14 - 18)</u>

That is Not Me: A Journey of Perception
By Lisa Nelson (2018, 198 pages)

- A memoir based on a poem by the author of her experiences growing up in the 1960s-70s with achondroplasia.

Dwarf: A Memoir
By Tiffanie DiDonato (2012, 272 pages)

- A woman’s memoir on her life with dwarfism and experience with limb-lengthening surgeries.

The Manager
By Caroline Stellings (2013, 183 pages)

- A novel about 17-year-old Ellie, and her sister Tina, an aspiring boxer with dwarfism. Set in a Nova Scotian town in the 1970s, the book uses humour to explore issues around prejudice relating to disability.

PARENTING BLOGS

Diary of a Little Chicken
(http://diaryofalittlechicken.blogspot.com/)

- Mother of a 3-year-old boy with achondroplasia.

A is for Adelaide
(https://aisforadelaide.com/)

- Mother of a 6-year-old daughter with achondroplasia.

Dwarf Aware
(https://dwarfaware.wordpress.com/)
- Mother to a young son with achondroplasia.

Scary Mommy
(https://www.scarymommy.com/baby-has-dwarfism)
- Not specifically about dwarfism but has an author that is the father of a child with dwarfism and he writes pieces sometimes.

Bloom
(http://bloom-parentingkidswithdisabilities.blogspot.com/)
- Holland-Bloorview affiliated blog on parenting children with disabilities.

Knoah's Arc (inactive)
(https://knoahsarc.wordpress.com/)
- Mother of a young boy with dwarfism.

Little Miss Ravenne (inactive)
(https://littlemissravenne.wordpress.com/)
- Mother of a young girl with dwarfism.

Tram Tales (inactive)
(http://tramenglish.blogspot.com/)
- Mother of a young girl with dwarfism.

MEDICAL RESOURCES

Doctors & Facilities

Eastern ON

Ottawa
- Dr. Wong at Jeanne D'Arc Medical Centre (Pediatrician)
- Dr. Kathryn Keely at Children's Hospital of Eastern Ontario (Pediatrician)
- Children's Hospital of Eastern Ontario (CHEO) for specialized surgeries

Northern ON

Thunder Bay
- Dr. Teresa Bruni at Thunder Bay Regional Health Sciences Centre (Pediatrician)
- Dr. Linda Bakovic at Thunder Bay Pediatrics (Pediatrician)
- George Jeffrey Children's Center (PT/OT)

Western ON

Kitchener / Waterloo /Guelph / Hamilton

- Dr. Andrew Latchman at McMaster University Hospital (Pediatrician; highly recommended)

Windsor

- John McGivney Children's Centre (PT/OT)

London

- Dr. Christopher Bailey at the London Health Sciences Centre (Orthopaedic Surgeon)

Southern ON

Brampton

- ErinoakKids Centre for Treatment and Development (PT/OT, speech therapy)

Toronto

- Dr. Michael Ford at Sunnybrook Hospital (Orthopaedic Spine and Trauma Surgeon) RETIRED
- Dr. Everton Gooden at North York General Hospital (Head and Neck Surgeon)
- Footprints Therapy (OT for children)
- Sick Kids Hospital
    - Sick Kids Bone Health Dysplasia Clinic
        - Dr. Roberto Mendoza-Londono (Clinical and Metabolic Genetics; LPO contact)
        - Dr. Andrew Howard (Orthopaedic Surgeon; LPO Contact)
        - Dr. Maryse Bouchard (Orthopaedic Surgeon; LPO Contact)
        - Lucie Dupuis (Genetic Counsellor; LPO contact)

      Dr. James Drake (Head and Neurosurgeon)
    - Dr. Reinhard Zeller (Orthopaedic Surgeon)
    - Dr. Simon Kelley (Orthopaedic Surgeon)
    - Sick Kid's Ronald McDonald House can provide sleeping accommodations for families coming from out of town for appointments. Many nearby hospitals have patient rates for families coming in for Sick Kids appointments as well. Sick Kids provides a list of these hospitals, found here: https://www.sickkids.ca/en/patients-visitors/planning-visit/staying-overnight/#accommodation

Rehabilitation Programs

Kidsability Program

- Provides a wide range of programs and services for children with a wide variety of special needs in the Waterloo region.

Holland-Bloorview Rehab

- Provides a wide range of programs and services for children with a wide variety of special needs in the GTA region, including recreational equipment rentals for clients and families (e.g. bikes), youth drop-in for ages 14-29, and an orthotics program.

PRACTICAL RESOURCES

Driving

Xxaminer Driver Consultant Inc.
50 Commercial Avenue, Suite 216, Ajax, ON L1S 2H5
(416-300-7073)

Young Drivers of Canada

- Driving school with many locations all over Ontario. Many LPs have reported having success with pedal extension accommodations here. However, they are on the more expensive side.

A1 Driving School

- Driving school with many locations all over Ontario. Many LPs have reported having success with pedal extension accommodations here.

Saint Elizabeth Health Care

- Has a Driver's Assessment and Training Program approved by the Ministry of Transportation that provides driving services to people with special mobility considerations. Includes medical assessments, vision waivers, assessments and training for vehicle adaptations, and more. There are locations in Toronto, Kingston, Whitby, Brampton, Oakville, Hamilton and St. Catharines.

Recreational Programs

Camp LPO

- Week-long summer camp run by LPO for children of short stature and their average-height siblings ages 7 to 14. LP children ages 15-16 can do leadership training and counsellors-in-training. LP children age 17 and older can work as staff and receive payment.

Track 3

- Track 3 is an Ontario-based non-profit organization dedicated to teaching youth with disabilities skiing and snowboarding.

SHOPPING GUIDES

Baby Gear

Bugaboo Frog Stroller

- Baby stroller recommended by parents of LP children.

Snuzzler
https://www.amazon.ca/Summer-Infant-Snuzzler-Support-Strollers/dp/B0051BOEGE

- Full-body support device for use in car and stroller seats. Infants with dwarfism have weak neck muscles and heavier-than-average heads so some parents prefer to use full-body supports in conjunction with their regular car seat for added protection against whiplash and airway obstruction.

Recreational Equipment & Toys

Yvolution 3-in-1 Glider
http://www.canadiantire.ca/en/pdp/yvolution-glider-3-in-1-0848904p.html

- Tricycle/scooter hybrid designed for very small children that can "grow" with your child. Many parents of younger LP children have found that this toy has suitable dimensions for their LP child and helps then "keep up". Can be ordered online or purchased in-store at Canadian Tire locations.

Power Wheels Wild Thing
https://www.walmart.ca/en/ip/fisher-price-power-wheels-wild-thing-ride-on/6000197564296

- A battery-powered vehicle similar to a toy car designed for very small children that many parents of younger LPs have recommended.

Kickboard
https://www.kickboard.ca/

- Manufacturers of 2-wheeled scooters, 3-wheeled kickboards, and balance bikes designed for kids. They make micro-scooters in very small sizes and the extra safety and balancing features make them especially suited for LPs. Can be ordered online or purchased in-person from the Toronto Warehouse.

Bike Friday
https://www.bikefriday.com/folding-bikes/

- Manufacturer of custom-built folding bikes. While bikes are designed and built for your measurements, they are not designed specifically for LPs like the above products are.

Pumper Car
https://www.pumpercar.com/

- Designed for children with special needs, the pumper car increases an LP's mobility and strength.

CCM Lucerne Bike
http://www.canadiantire.ca/en/pdp/ccm-lucerne-kids-bike-18-in-0711174p.html

- Although not specifically designed for LPs, parents have reported success with adjusting product to fit child. Available at Canadian Tire.

Bike Helmets

- Many LP children's heads do not fit standard children's bike helmets. Parents have found luck with purchasing adult men helmets with an adjustable dial at the back with foam and padding to ensure it fits snugly.

Ear Bandit
http://www.earbandit.com/

- Manufactures water earplugs and swimming headbands designed for children with inner ear tubes or inner ear perforations (common among people with achondroplasia).

For Small Hands
https://www.forsmallhands.com/

- An online store with toys and art supplies designed for very young children. Many of their products are suitable for LPs and have extra grip and ergonomic support.

Clothing

Younger Children

While it is much easier to find age-appropriate clothing for younger children, many parents still need to alter their child's clothing. Some brands that parents of LP children recommend are Oshkosh, Carter's, and Gagou Tagou.

Oli & Bou
https://www.olibou.com/

- Oli & Bou is a Canadian company based in Montreal that designs clothing specifically for children with achondroplasia.

Teens

Auf Augenhoehe
https://www.aufaugenhoehe.design/collections/all

- Fashion label designed specifically for adults with achondroplasia. Good for teenagers who have difficulty finding age-appropriate clothing.

Kathy D. Woods
http://www.kathydwoodsstore.com/

- Fashion label designed specifically for adults with achondroplasia. Kathy D. Woods is more teen-appropriate than Aug Augenhoeh and sells jeans tailored specifically for people with achondroplasia.

International Sourcing

Some LPs have had luck ordering clothing online from Chinese retailers because their sizes run much smaller than standard North American sizes and many retailers stock XXXXS and XXXS sizes.

Wheelchair Friendly

Silverts
https://www.silverts.com/show.php/list/women/-/wheelchair

- Canadian retailer with a wide range of adaptive clothing, including clothing designed specifically for wheelchair users.

Shoes

Women's & Girl's Shoes

Cinderella of Boston
http://www.cinderellaofboston.com/

- Petite women's footwear from sizes 2 – 5 ½. Many fashionable styles including casual shoes, heels, and sandals.

The Little Shoe Store
https://www.thelittleshoestore.com/

- Fashionable footwear designed specifically for LP women.

Top Rated Shoes
https://topratedshoes.com/

- Canadian retailer of fashionable women's shoes starting at size 2.

Adaptive Equipment for Around the House

American Standard Baby Devoro 1.28 gpf FloWise 10 Inch High Round Front Toilet

Kohler Primary Open-Front Toilet Seat

- Modified toilet seat designed for very young/small children while still resembling a "normal" toilet seat. Other parents have had success with installing this seat in a school washroom. Available at Home Depot.

Aqueduck Faucet and Handle Extenders
https://www.aqueduck.com/

- Makes faucet extenders and handle extenders to help LPs wash hands; also useful for art rooms/school kitchens. Parents have recommended the 2-handle extender. Available online or in-store at Bed Bath and Beyond.

Ikea Stepping Stools
https://www.ikea.com/ca/en/
Ikea makes a variety of affordable stepping stools that LPs have vouched for.

Adam's Manufacturing Step Stools
https://www.amazon.com/Adams-Manufacturing-8530-02-3731-Quik-Fold-Stool/dp/B0018194QG
https://www.walmart.com/ip/Adams-Folding-Step-Stool-Black/14983364

- Manufacturer of lightweight folding 1-step stools which can be easily transported. Adam's stools feature extra grip treads and non-slip floor protection.

Jeronic Kingdom
http://www.jeronic-kingdom.com/

- Manufactures a wide variety of stepping stools suitable for LPs.

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