



Alberta Association for  
**Community Living**  
serving children and adults with  
developmental disabilities for over 50 years

## Provincial Office

11724 Kingsway Avenue  
Edmonton, AB T5G 0X5  
Phone 780.451.3055  
Toll Free 1.800.252.7556  
Email: [mail@aacl.org](mailto:mail@aacl.org)  
Website: [www.aacl.org](http://www.aacl.org)

## Regional Office

4112 - 4 Street, NW  
Calgary, AB T2K 1A2  
Phone: 403.717.0361  
Fax: 403.228.2132

# Acknowledgements

This Pocket Guide to Advocacy should not be considered a comprehensive guide to advocacy. The purpose of this small Pocket Guide is to outline key points for parents that can be readily consulted when you find yourself in an advocacy situation. As it is a general guide, it does not cover specific situations in detail.

Funding for this guide was provided by a grant from Persons with Developmental Disabilities, Edmonton Region Community Board. The opinions in this guide are exclusively those of Alberta Association for Community Living and are in no way representative of the views or opinions of Persons with Developmental Disabilities Edmonton Region Community Board.





# Table of Contents

## Introduction

Advocacy is inevitable – if you love or care about someone with developmental disabilities . . . . . 1

When advocacy will be required is not always predictable . . . . . 4

Most of us aren’t trained to be advocates . . . . . 5

Uncertainty, as an advocate, is a given . . . . . 6

## First Steps

Vision – develop and continually refine your vision for your son or daughter . . . . . 7

Pathway – pursue a normative pathway as much as possible . . . . . 9

Relationships – the basis of a lifelong commitment to advocate . . . . . 11

Be confident – know your vulnerabilities . . . . . 14

## Taking Action

Preparation – the meeting . . . . . 17

Get organized – keep track of everything . . . . . 18

Know what you want to achieve – be clear on your expectations . . . . . 19

Gather information – connect to other families and to an advocacy organization . . . . . 20

Compromises – know your fall back position in advance . . . . . 23

Friends and advocates – always try to bring a friend or an advocate with you . . . . . 27

Speak to the right person – the person with the authority to make the decision . . . . . 28

Communication – listen carefully . . . . . 28

Formal advocacy and appeals – get help from an advocacy organization . . 29

Family advocacy - changing lives: changing communities . . . . . 30

Notes . . . . . 31

Advocacy Checklist . . . . . 32

# Introduction

Advocacy is inevitable – if you love or care about someone with developmental disabilities



The inevitability of advocacy is particularly true when parents share a desire for an inclusive life for their son or daughter with developmental disabilities: for their children to have a good life in community. Advocacy in itself does not imply a struggle or an adversarial process. Every parent advocates for the well-being of the children whether or not they

have a disability. Our society expects this of parents and implies one is a good, caring, conscientious and loving parent when they advocate for the best interests of their child. Advocacy on behalf of your son or daughter with developmental disabilities is no different and as such is a positive reflection of your commitment and concern for the best interests of your son or daughter.

Advocacy benefits the community and society as a whole. Taking action to improve the lives of individuals with developmental disabilities or sustain positive life circumstances (e.g., inclusive education, living in one's own home, etc.) creates a better community for all.

*Advocacy sharpens your capacity to critically view what is just and unjust within our communities and what must be done to foster needed social change.*

Speaking for people or supporting people to speak for themselves who cannot speak or have difficulty speaking on their own behalf who cannot do so easily or well while representing their interests as if they were your very own, is a societal good. Standing up for and with people with developmental disabilities to ensure they can assume their

rightful place as participating community members is a good, just and moral action. The above speaks to the essence of what it means to be an advocate.

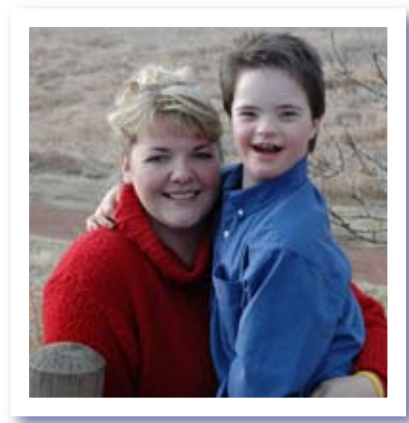


Advocacy is also of benefit to the advocate, not just the person for whom one is advocating or for society in general. If you take up advocacy it sharpens your capacity to critically view what is just and unjust within our communities and what must be done to foster needed social change.




Yet so many families, who by necessity, must act as advocates for their sons and daughters with developmental disabilities often find that their advocacy is viewed as less than positive. In truth, many parents will be viewed negatively and seriously for advocating on behalf of their children with disabilities. The positive aspects of advocacy, commonly accepted as an indicator of good parenting or a societal benefit, are somehow lost or forgotten when the advocacy is on behalf of someone with a developmental disability.

The simple truth of this familiar experience for all too many parents rests on the fact our communities and society does not yet fully value individuals with developmental disabilities, and inclusion is not typical or ordinary. Nor is inclusion likely to be readily offered or lasting across the lifetime of a person with developmental disabilities.



And many of the supports and services families and individuals with developmental disabilities may need are not necessarily family friendly or easily secured.

Thus, it is inevitable parents will find themselves having to advocate, and repeatedly so if not continuously, on behalf of their son or daughter with developmental disabilities. For the reasons noted above, this advocacy, however good and necessary, will not always be appreciated. Given that advocacy is inevitable, it makes sense to be prepared and knowledgeable and to also remember that advocacy is a necessary and beneficial societal good.



Given the inevitability of advocacy and the need for advocacy across the lifetime of someone with developmental disabilities, parents not only need to learn to be strategic and knowledgeable advocates, they need to be able to sustain their passion and commitment. The best and most powerful way to do this as a parent is to be connected to a family advocacy network or organization committed to inclusion. Organizations like Alberta Association for Community Living (AACL) provide many avenues (e.g., workshops, conferences, leadership series, advocacy staff, family networks, local associations, etc.) for parents to become successful and lifelong advocates. For more than 50 years, generations of parents have found strength and renewed capacity through their connection to other parents who share a common vision and common understanding.

## When advocacy will be required is not always predictable

Sometimes you will know in advance that your advocacy skills will be needed (e.g., when a meeting is being held to discuss eligibility for services or funding or to discuss school placement), but there are many other times you will not be able to anticipate when your advocacy skills will be required. It is best to always be expecting advocacy will be required. This way you can be ready rather than surprised and if you find that advocacy isn't needed, it is easier to relax than gear up for advocacy unexpectedly. Of course, you can always keep this guide handy – in a purse, pocket, briefcase, etc. - so you can refer to it periodically.




## Most parents are not trained to be advocates

Many parents have said they were never prepared to be the kind of advocate a child with disabilities requires—evervigilant, knowledgeable, prepared to challenge government or other authorities. There are not many examples when in preparing for parenthood the subject of advocacy comes up. So in addition to having to learn to parent a child with disabilities, parents also have to learn to be advocates to ensure they have the supports they require and their son or daughter has access to the supports they need (e.g., the regular classroom, a home, friends, meaningful employment, an interesting life).



Fortunately, everyone can learn to be a better advocate and a lifelong commitment to continuing to learn will make a difference to your child's future and the children with disabilities who follow after. Make a point of finding the parent

advocacy organizations in your community or province and what they offer by way of training, information and assistance in being an advocate. While the Internet has become a vital source of information, it cannot and does not replace the unique value and knowledge parents gain from being together to share their stories, dreams and challenges.



*Self-doubts as an advocate are natural and while they can help you think about how to improve your advocacy skills, it's important that these natural self-doubts do not overwhelm or paralyze you.*

## Uncertainty, as an advocate, is a given

When you are advocating for someone you love or care deeply about you are naturally going to worry and ask yourself questions before, during or after an advocacy “moment” – “am I doing the right things, am I making the right compromises, am I taking the right stand at the right time in the right way, am I saying the right things?” After an advocacy “moment”, you may find yourself having doubts – if only I had said this instead of that, I shouldn't have gotten angry or cried. You may even believe if only you had said or done something different then things would have gone better.


Self-doubts as an advocate are natural and while they can help you think about how to improve your advocacy skills, it's important that these natural self-doubts do not overwhelm or paralyze you. It is rarely true that if you said something different or behaved differently things would have turned out better – it is as likely they might have been worse. It is more important to move on and figure out the next steps - if any are needed.

# First Steps

## Vision – develop and continually refine your vision for your son or daughter

The clarity of your vision for your son or daughter's inclusive future is critical to any successful advocacy. A vision that clearly identifies in your mind your child's rightful place in the world is essential to the pursuit of an inclusive life: to a good life in the community. Once you have it clear in your mind, you also need to be able to share it, describe it and explain it to others. This something you can practice. Some families write it down and review it periodically. Others find it helpful to share it out loud at first with those who are likely to be supportive and positive before sharing it in a less friendly environment.






A clear but continually refined vision will be necessary as your child grows and becomes more of their own person and as advocacy will be required over the course of their lifetime. As children get older and become adults, they can increasingly develop and articulate, to the degree possible, the vision they hold for themselves.

There are different processes you can use to develop your vision from the informal to the more formal, including workshops for parents on how to develop a vision. Which process you use is not as important as the clarity with which you hold that vision. Clarity is fundamental: as over the course of a lifetime there will be many individuals and authorities that will not understand your vision, agree with it or believe in it.

When you are confused about your vision or it is not clear to you, when you are not sure what is right or needed, you will be in a weaker advocacy position. Similarly, if you are a couple it is critical at least when advocating for your child you agree on a common vision. If you have differences, it is best not to bring them into an advocacy context or your differences, may be used against you. These moments of confusion, differences or blurred vision are common to everyone's experience and are unavoidable. They are best treated as moments designed to help you get greater clarity over time. However, these are not ideal moments to engage in advocacy, particularly if the issue is significant or life-defining.\* At these times it is best, if you can, to postpone any immediate advocacy until you are clearer and more certain of your vision.

*\*Life-defining refers to actions or decisions that may be important or powerful enough to influence the course of someone's life.*



While you may be clear on your vision it does not mean that others will necessarily agree or understand. Sometimes this is a result of how well we are able to explain the vision, but it is more likely that others do not share the same vision. The first can be addressed by more practice or using visual materials, (i.e., a book or DVD\*\*) while the latter explains why some differences cannot be bridged.

As will be explained later, your vision is the benchmark you will use to determine which compromises you might make and which you will not.

*\*\* Some parents have found it useful to use AACL's book, titled Inclusive post-secondary education for adults with developmental disabilities: A promising path to an inclusive life, and accompanying DVD, Inclusive Post Secondary Education, Living the Dream, as a way of sharing their vision with teachers and principals.*

## Pathway – pursue a normative pathway as much as possible

Often the means to achieving the vision of an inclusive life is to pursue a normative pathway. A normative pathway is the path most people in our society typically follow through life. For example, children go to school, participate in recreational activities after school and go to birthday parties; teenagers hang out, some work on weekends, many develop particular tastes in music and clothing; young adults go on to college, university or work and as they get older they start to look at having a home of their own. You can find the normative pathways of all communities by being conscious of the pathways children or adults without disabilities and of a similar age to your son or daughter are following. Then as much as possible, try to have your son or daughter included within those normative pathways.


It is not always possible to follow a normative pathway all of the time. What is important is that you try as much as possible to do so and that whenever the path veers towards segregation or marginalization, you try to minimize this and ensure those parts of the pathway that are inclusive remain so.

One of the purposes of advocacy is to help you keep your son or daughter on as normative pathway as possible to an inclusive life. If the pathway isn't reasonably clear to you, then as with your vision, it is more likely you will lose sight of the path. When you are in an advocacy situation you want to be able to keep your vision and the pathway to that vision as clear



as possible. In effect, the goal of your advocacy is to stay as close to a normative pathway as possible to achieve the vision of an inclusive life.

The combination of a clear vision and the pursuit of an inclusive and normative pathway is the most powerful means of realizing a good life for your son or daughter with developmental disabilities. The most powerful means of creating possibilities – possibilities for learning, friendships, employment and being seen and recognized as valued and needed by others is why families are called to be advocates.



*It is helpful to remember that the basis for your advocacy rests on your love for your son or daughter and your desire for them to have every opportunity for a meaningful life.*

## Relationships – the basis of a lifelong commitment to advocate

It is helpful to remember that the basis for your advocacy rests on your love for your son or daughter and your desire for them to have every opportunity for a meaningful life. Further, it rests on a lifelong commitment and the hope that the actions you take during your lifetime contribute to a continuing good life for your child after you are no longer alive. The point here is to emphasize the differences between yourself and any other party when you are engaged in advocacy.

The interests of others in the well-being of your son or daughter, regardless of their good intentions, will never be equivalent to your own. In almost every advocacy situation, the interests of others will be based on a short-term involvement and the other party will have allegiances to other interests (e.g., their beliefs and values, agency policies, budgets, staff, etc.).

As such, never accept the statements, “We are all here for the same reason,” or “We all have the same interests in doing what is best,” and



all manner of the same, at face value. These statements, whatever their actual intention, misrepresent the true interests of everyone involved. These statements tend to make families feel there is something wrong with their advocacy when they do not agree with the system's representatives who claim to be acting in the best interests of the person with developmental disabilities.


It is helpful as well to realize that you will experience many differences in the advocacy situation than the other parties' experience. For example, time itself will have different meaning for each you. If you are waiting to learn if your child will be accepted into a regular classroom or if your son or daughter will receive the funding needed to support them in their own home, then the passage of time will have its own particular agony. This will not be true for those making the decision, their child's life is not on hold and their procedures have their own time frame.



Words will not mean the same thing. When a principal tells you, after you have expressly stated your desire for your child to be included, that you should visit the segregated classroom to be sure – you will hear your child is not wanted while the principal may only think he or she is making sure you have considered your options. Now you are angry and hurt because your child’s worth and belonging have been threatened and the principal cannot understand where your anger or hurt comes from.



Time and words are just two examples, but the differences will hold true on many levels. Knowing this can sometimes make it easier to understand your fears, anger and frustrations given that it is your son or daughter’s life that is at stake. It can, as well, help to explain why sometimes there is an impasse of understanding, why there is a “failure to communicate” or to understand each other.



You can learn from these experiences and become a stronger and more capable advocate by, for example, not accepting the time it will take to make a decision that should be made quickly or simply refusing to visit a segregated classroom because you do not have to see where you do not want your child educated. You can see the regular classroom and know that is where your child belongs and deserves to be educated.

## Be Confident – know your vulnerabilities

Most people become nervous when they have to engage in advocacy. Worried, as noted earlier, that they might say the wrong thing, lose their temper or cry. One of the best ways to build your confidence, in addition to being prepared and having the support of an advocate or friend, is to know your vulnerabilities. For example, if you know you are likely to lose your cool or breakdown when someone devalues the presence of your son or daughter, then you can think about how to prepare yourself. At that point you may want to take a break (officially or unofficially [for example, going to the bathroom]), have your advocate or ally respond or having prepared yourself for this moment, take a deep breath and take your time responding.

Be confident and emotional, you are advocating for someone you care deeply about and whose life will be affected by the decision. Being emotional about your son or daughter is a requirement as a parent. Use your commitment to fuel your confidence.

Being confident can help you resist the urge to compromise when you should be holding your ground. It is expected that to demonstrate good faith parents will cooperate with those in authority, those who make funding, eligibility, support or acceptance decisions. Most of us want to be cooperative and even want to be liked. We worry if we are negative or aggressive we will either not get what we want and/or our children will be badly treated. The opposite is assumed to be true – that if we are nice and logical then we will be heard, understood, our request accommodated and our son or daughter well looked after.



First, it is rarely true that how you behave determines how your son or daughter will be treated. Being nice will not result in those who resist inclusion suddenly valuing the presence of your son or daughter. Other strategies will be required to change people's hearts if inclusion is the outcome you desire from a system that is initially or persistently resistant.

Cooperate and be pleasant when possible, but do not mistake cooperation and pleasantness as more valued than taking a stand on what is right and true, particularly when the life of your son or

daughter is affected. Rarely do those who are opposed to inclusion change their mind because someone is nice to them. You do not have to be angry or aggressive, but being assertive is valid when it is your son or daughter who is relying on you to protect their well-being and future. And cooperation and compromise are not the same thing. You can cooperate but not agree or compromise, especially on the question of the value and worth of your son or daughter.

If you can find common ground to move forward from or establish a basis for trust with those you find yourself in an advocacy situation with, you should capitalize on this. It is important to be strategic and tactical not simply, for example, assume if you repeat what you want over and over again you will finally be understood. Being tactical, by example, may mean bringing someone to the meeting with you or making sure you have as many people joining you as the other parties bring to the table. It can mean being well organized, taking exhaustive notes and keeping all your information organized in a binder. Being strategic can mean having talked to other parents or allies who have



experience with the advocacy matter at hand. For example, talking to families who have been successful in securing the same or similar family supports to the ones you want. Either learning the legislation or policies that govern the advocacy arena you are addressing or having an advocate who has that knowledge accompany you.



# Taking Action

## Preparation – the meeting

While it may seem obvious, there are a few routine things to consider when heading into an advocacy situation. For meetings these include knowing:

- Who will be at the meeting (if there is a cast of thousands try to pare it down or postpone the meeting to arrange your own supporting cast);
- Who has the authority to make the necessary decisions (ideally, this is who you want at the meeting);
- Who you need or want attending the meeting;
- Who will be taking notes (always take your own notes or better yet have someone do this for you so you can concentrate on what is being discussed);
- Who will chair or facilitate the meeting;
- Who you will bring as a representative (you are always entitled to bring an advocate, just let the other party know you will be accompanied to the meeting.) If the other party refuses to allow you to bring an advocate or representative, then postpone the meeting until this is resolved. Do not attend meetings where the terms of the meeting have been planned unilaterally;
- How long the meeting will be scheduled for;
- How much time you will have to present your request and remember to ensure the amount of time works for you;
- If you have access to the same information as everyone else at the meeting, what the agenda is and that it addresses your concerns.

It is a common and extremely helpful advocacy truism to never go to a meeting alone – always bring someone with you to either morally or practically support you. And never go into an advocacy meeting without being prepared.

## Get organized – keep track of everything

Given that the need for advocacy is inevitable, it is wise to maintain an organized file folder or binder, with topic dividers of all documents and correspondence in chronological order, including emails, related to your son or daughter with developmental disabilities. It is quite possible you may never have a serious advocacy situation which ends up in formal appeal process, but it is always an advantage to have an organized set of papers should this happen. If you also find you need more formal advocacy assistance it is much harder to organize the information after the fact.

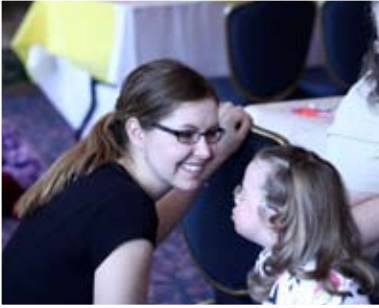


If you find yourself heading into what might be an advocacy matter, it is best to keep a log. The log is where you should record by date every contact you have in the advocacy matter. This includes phone calls, emails and meetings. Note who you spoke to, emailed or met.



Make certain you get their full names and positions. Ideally, you will also keep track of what was said at any meetings or during phone conversations. As stated previously, keep all your papers in one location and make sure you get a copy of everything the other parties have access to.

This does seem like a lot of work, but it will be a tremendous help in more difficult and prolonged advocacy matter.



## Know what you want to achieve – be clear on your expectations

Whether you are seeking support for your family or direct support for your son or daughter, it is best to know what you specifically require or desire before you go into a meeting or begin negotiations. As with other points in this guide, clarity is very helpful to the advocacy process. If you are not clear on what you need and hope to achieve you are in effect relying on the system to do the right thing by you and your family. And while on occasion this does happen, it is a matter of luck and not effective planning.

You simply cannot rely on the system to help you figure out what you need or what you are entitled to. You may have a good person to deal with at one moment in time, but there is no guarantee and little likelihood that person will be there over time. In addition, if the bureaucracy changes the rules, you may find that a formerly good person is now required to provide you with less information or simply protect the system's bottom-line by approving less support than is essential.

It is a good idea to have what you want to achieve and the points you want to cover written down. Also, most advocates recommend bringing photos of the person you are advocating for if they are not attending the meeting. Sharing the picture and some information about the individual helps to remind everyone that there is a real person whose life will be affected by the decisions being considered.

## Gather Information – connect to other families and to an advocacy organization

This item covers two points. The first relates to those times when you are unsure of what your family or son or daughter might need. For example, many families may feel they need support at home but are unsure of how that support can be best provided to make the greatest difference in their lives. And many families are uncertain



of what can or should be done to facilitate their son or daughter's transition to adulthood. Many thousands of families have already been through these experiences, so while you might at times feel alone and uncertain, there is a tremendous amount of wisdom and knowledge available by connecting to other families and advocacy organizations (whose knowledge is based on the experience of families). Learning from their experiences means you can develop the options or ideas that would work best for your family or your son or daughter.

The second point relates to knowing what is available by learning what other families have accomplished. It is rare that you will find the system sharing all that is available or assisting you in crafting individualized, personalized and creative options. By being connected to a family organization or an advocacy organization you will gain invaluable information on both what systems have to offer and what other families learned from their advocacy.



For example, did you know that while a principal may tell you they cannot include your child because they lack the funds or if a principal tells you your child can be included but without the necessary supports because they lack the funding to provide those supports, this can be used to your advantage. While principals may honestly believe they lack funding they do not need to provide supports or include a child, they are in fact incorrect. When funding is raised it is almost always best not to argue immediately but rather get the reasons for excluding your child or failing to provide adequate supports in writing or otherwise witnessed and recorded. In effect, you are being told there is agreement that your child should be included but the only issue is money. This agreement is important and fundamental.

By law children cannot be excluded or denied support due to funding and with the involvement of knowledgeable advocates almost every one of these situations ends up with a child being fully included. Achieving a quality education, however, can be another advocacy matter.



To summarize, families have found strength in connecting to each other (locally, regionally, provincially, nationally) in an organized context and on the basis of common interests or values for over 50 years. There is comfort in knowing you are not alone and the greater likelihood of dreams being sustained and realized in the company of other families.

*Being equally valued and given their vulnerabilities, individuals with developmental disabilities are entitled to the best and deserving of the best.*

Lastly, as noted previously, you may also want to read any relevant policies, regulations, ministerial orders or legislation that governs the matter under negotiation. Policies typically do not have the force of law but rather guide practice. As such, policies can be flexible or overridden at times in the interests of families.

## Compromises – know your fall back position in advance

Compromise is inevitable in every relationship but when one party to the compromise is far more vulnerable than the other, any compromise needs to be very carefully considered. When one party is particularly vulnerable, as is true for a child or person with developmental disabilities, then any compromise must take these vulnerabilities into account. The interests of both parties in this instance are not equal and the compromise must first serve the interests of the vulnerable party.





Having noted earlier the need for clarity of vision and pursuit of an inclusive pathway through life, these points can serve to anchor your approach to any potential compromise. Also noted earlier, is the point about needing to be clear on what you hope to achieve through advocacy. These three things form the basis for determining what your fall back position or compromise might be from what you truly hope to achieve: a position you should have in mind before you enter into any advocacy or negotiations and a position you should only move to when absolutely necessary rather than something to be considered early in any advocacy.

Compromises should never be measured from the point of view that things could be worse. This approach devalues your child or the person with developmental disabilities. There is nothing about having developmental disabilities that suggests individuals should settle for the least worst option unless one believes people with developmental disabilities are second-class human beings. Being equally valued and given their vulnerabilities, individuals with developmental disabilities





are entitled to the best and deserving of the best. By measuring any compromise from the vision, pathway and objective of the advocacy you will vary as little as possible from these ideals, you will know how you have varied, what the effects of the variation will be and you will know what will be required if you need to regain the ideal.

The tendency to compromise unnecessarily is closely tied to the desire most people have to cooperate and the pressure applied within our culture to be cooperative.

Most parents believe if they are rational and logical, compromising here and there, the system will be considerate and responsive. This is rarely true. Little is gained by compromises in comparison to what is gained by being firm, clear and holding your ground. Many families will be told there are rules and procedures that prevent the system from doing the right, as if these are literally carved in stone, when in many instances these rules and procedures can be altered. Keep your eyes on what needs to be done and try not to be distracted by the roadblocks that might be put in your way.



There is a particular form of compromise that many families find hard to avoid when seeking inclusion. As most systems are organized around offering segregated or group programs for children and adults with developmental disabilities, families will be more readily offered this option. To disguise the reality of these options they will often have nice names attached to them and rarely will they be described as segregated or congregated (i.e., grouping people with disabilities together). These segregated options may be offered part-time with the idea that in exchange for their agreeing to some inclusion you should agree to some part-time segregation. This is a very dangerous compromise that almost always leads to increased segregation over time. Avoid this compromise if at all possible.

In addition, most families are never advised of the facts that are well-established with respect to segregation. For example, individuals that are segregated are more vulnerable to abuse and violence. Inclusion provides the greatest degree of



safety and security. Segregated programs will be described as offering trained staff or specific interventions or programs expertly designed for people with developmental disabilities. Again, research has shown that in segregated programs individuals with developmental disabilities receive less instruction or individual attention than in inclusive environments. Therapeutic interventions work best when delivered in inclusive settings.

Things are not always what they seem – think twice or more when choosing between your well-thought out desire for inclusion and offers that may knock your son or daughter off the path to an inclusive life with possibilities and promise.

## Friends and advocates – always try to bring a friend or an advocate with you

Although not always possible, but worth noting again, it is best to have a friend or an advocate accompany you to meetings. An experienced advocate can help support you through the advocacy process and at the very least a friend can offer moral support, take notes, remind you of points you wanted to cover, step in (if you have agreed to this) when you need a break and bear witness to what is being said. Systems tend to behave better when there is a witness to their actions and statements.





## Speak to the right person – the person with the authority to make the decision

A common problem in advocacy occurs when the person you are meeting or negotiating with does not have the authority to make the decision you require. Whenever possible try to meet with the person who does have the authority. If this is not possible try to identify who exactly in the chain of command of the system has the authority. You might also be able to identify the steps you need to go through to reach the person with the power to make the decision. Try to know this before you begin the advocacy process. When this is possible you might choose not to waste too much time trying to convince those who do not have the authority but simply engage them to the degree necessary so you can proceed up the chain of command.

## Communication – listen carefully

Most people worry about what they will say and how they will say it. Will they be even-toned, rational and logical? While it is fine to consider how you will make your case, one thing many people miss, especially in the emotion or intensity of an advocacy situation, is to listen carefully. Listening carefully may give you insight into the other person's perspective and provide strategic clues as to how you might frame your points so that you too will be heard. There are times in advocacy situations when you may think you have reached a common understanding only to learn later you misunderstood each other. Listening carefully can help to ensure that areas of agreement and disagreement are clearly understood.

It is important to hear what is not being said as well as to watch body language. This is where having someone with you in the meeting can be helpful because it is hard to pay attention to everything that is happening.

At times it might be a good idea to take a break. You may choose to do this when you want to strategize or review things with your advocate, when things are tense or when you have an offer you need time to consider.

## Formal advocacy and appeals – get help from an advocacy organization

This Pocket Guide to Advocacy is not designed to address more formal advocacy and appeal situations. More formal advocacy situations can be defined as those times when experts and/or lawyers are involved. In principle, families should not enter into formal advocacy situations without their own experts or lawyer as the situation warrants. Our advice to families is that if you arrive at a meeting where lawyers or experts are in attendance and you were not forewarned to cancel the meeting and reschedule.



If you find yourself involved in an appeal or a formal review of a decision, then you should seriously consider getting help from an advocacy association. For example, you may read in the procedure for the review or appeal that the decision of the appeal panel or review committee is final and not realize that there might still be the possibility of a judicial review. A professional advocate can ensure you are aware of your rights.



## Family Advocacy – Changing Lives: Changing Communities

Families advocating individually and collectively make a difference. It is family advocacy that established a right to education in Alberta and the right to a formal appeal process; that established inclusive education and inclusive post-secondary education; and that established family supports and community living. It is only family advocacy that will end institutionalization and prevent its re-emergence.

It is only family advocacy that will reduce the segregation that exists today and only family advocacy that, over time, will increase inclusion. The possibility of a more promising future rests entirely on the capacity of families to pursue their vision of a meaningful and inclusive life.



# Advocacy Checklist

## Introduction

- Advocacy is inevitable – if you love or care about someone with developmental disabilities
- When advocacy will be required is not always predictable
- Most of us aren't trained to be advocates
- Uncertainty, as an advocate, is a given

## First Steps

- Vision – develop and continually refine your vision for your son or daughter
- Pathway – pursue a normative pathway as much as possible
- Relationships – the basis of a lifelong commitment to advocacy
- Be confident – know your vulnerabilities

## Taking Action

- Preparation – the meeting
- Get organized – keep track of everything
- Know what you want to achieve – be clear on your expectations
- Gather information – connect to other families and to an advocacy organization
- Compromises – know your fall back position in advance
- Friends and advocates – always try to bring a friend or an advocate with you
- Speak to the right person – the person with the authority to make the decision
- Communication – listen carefully
- Formal advocacy and appeals – get help from an advocacy organization
- Family advocacy - changing lives: changing communities



ALBERTA ASSOCIATION FOR  
**Community Living**

servicing children and adults with  
developmental disabilities for over 50 years

We are a family-based, not-for-profit organization representing thousands of children and adults with developmental disabilities and their families. Our dream, which began more than 50 years ago, is for meaningful family and community life for our sons and daughters. This dream lives on today and people with developmental disabilities and their families remain at the heart of AACL.

We believe families are at the heart of community and children and adults with developmental disabilities should have the opportunity and support to grow up in a family, have a home in the community, be educated in inclusive classrooms, develop friendships and participate in and contribute to the life of their community. An inclusive community is a welcoming community and everyone shares in the responsibility to create inclusive opportunities.

### **Provincial Office**

11724 Kingsway Avenue

Edmonton, AB T5G 0X5

Phone: 780.451.3055

Toll Free: 1.800.252.7556

### **Regional Office**

4112 - 4 Street, NW

Calgary, AB T2K 1A2

Phone: 403.717.0361

Email: [mail@aacl.org](mailto:mail@aacl.org)

Website: [www.aacl.org](http://www.aacl.org)





Alberta Association for  
**Community Living**  
serving children and adults with  
developmental disabilities for over 50 years

## Provincial Office

11724 Kingsway Avenue  
Edmonton, AB T5G 0X5  
Phone 780.451.3055  
Toll Free 1.800.252.7556  
Email: [mail@aacl.org](mailto:mail@aacl.org)  
Website: [www.aacl.org](http://www.aacl.org)

## Regional Office

4112 - 4 Street, NW  
Calgary, AB T2K 1A2  
Phone: 403.717.0361  
Fax: 403.228.2132