

Developing Positive Interactions for People with Developmental Disabilities and First Responders, Police, and the Justice System:

**A Guide for People with Developmental
Disabilities and their Loved Ones**



This guide is brought to you by The Arc of Northern Virginia

November 2016

Dedication

The Arc of Northern Virginia is dedicated to ensuring that the human and civil rights of people with developmental disabilities are protected. We have known and worked with thousands of families in our more than 50 year history who have taught us so much.

In recent years, we have seen a big increase in calls and emails from families who are concerned about the safety of their loved ones with developmental disabilities in police and other justice interactions. We have also had more calls from families saying their loved one has been arrested and they need help.

This guide is dedicated to those families who have trusted us in their time of need, allowed us to help in any way we could, and who have taught us so much about people with developmental disabilities in the justice system. The brave individuals with disabilities who have been through this process have paved a path and laid a knowledge base for our community. We wish everyone the happiest, healthiest, safest of lives.

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About The Arc

The Arc is the largest national non-profit community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. There are nearly 700 chapters across the country.

The Arc of Northern Virginia serves Arlington, Alexandria City, Fairfax, Fairfax City, and the City of Falls Church. The chapter's primary focus is on advocacy and providing information and resources to people with disabilities and their families. The chapter operates a Special Needs Trust program and offers some case management and guardianship services.

Our Partners

The Arc chapters work together to support one another and look at our broader community for other partners on varying subjects. As we have seen issues and needs in the arena of criminal justice arise, we have reached out to partners in that arena to help us.

The Reason for this Guide

As we have seen an increase in calls and concerns from family about interactions of people with developmental disabilities (DD), including intellectual disabilities, and emergency services and the courts, we knew we wanted to take action to help. Core services of The Arc of Northern Virginia are the provision of free information and referrals as well as advocacy. This guide is meant to meet the needs of people with developmental disabilities and their loved ones by doing what we do best—providing free, actionable information and helping people with developmental disabilities and their families advocate for themselves and others.

BIG TAKEAWAY

Look for this box in each section of the guide to help you hone in on key points

One Family's Story*

My youngest son, Todd, proceeded to disclose that his brother, Daniel, age 57 who is intellectually disabled, had been discovered looking at child pornography (CP) at his federal government job in DC. Todd had just returned from Daniel's apartment in Virginia where Daniel was questioned by a detective and an Inspector General Officer after being read Garrity Rights. Daniel signed a multi-page statement without an advocate present. His brother came as he was signing the statement.

Todd found out that Daniel's viewing had been discovered in April and his office computers were confiscated. He was put on paid administrative leave. Daniel did not know why his computers were taken or why he was put on leave. He was questioned by an officer from the Inspector General's office with his union steward present. His union steward advised Daniel not to say anything without an attorney present, but Daniel believed that he should answer whatever he was asked. When asked if he had ever "distributed" child pornography, he answered "No, I only sent it to my home computer in Virginia." He did not tell his brother or family what had happened at the time.

This began an experience in the criminal justice system in Virginia that lasted 15 months with \$60,000 in legal, psychological evaluations and counselor expenses. The fear and terror for a man with a childlike mind and for his family who had helped Daniel with adaptation to mainstream society was immense. Coordination of a team of professionals who did not appear to have experience with people who are intellectually disabled added to our anxiety.

Those professionals were willing to learn and their efforts led to Daniel's being found incompetent to stand trial. The charges were dismissed. There is an arrest record and the aftermath of the experience left his family fearful and protective. Daniel is able to learn and follow rules but "there is no big sign out there that says watching child pornography is a crime," he told his counselor. I contrast that with the Ten Commandments that are listed on tablets that are ubiquitous and easy to read.

As a parent, age 82, I did not know:

1. The dangers of the internet to a vulnerable person;
2. The criminal consequences for a victim of the internet's predatory dark side;
3. The lack of ability of law enforcement to halt child pornography on the internet in spite of its criminal consequences to vulnerable people;
4. The "lock 'em up" political climate that surrounds the viewing of child pornography and the lack of understanding of people with I/DD/autism who are not predators; and
5. The "civil death" that occurs when someone is put on a sex offender registry.

To anyone reading this manual, I beg you to fight for the person with a disability. Learn about their condition and educate the prosecutorial and defense professionals that you come in contact with. Work with your local Arc to gain the resources that will make you better. Contact attorneys around the country who do have experience with the condition and learn from what they have to teach.

**Names changed*

Mislabeled a Sex Offender: The Kelmar Family's Fight for Justice

Reprinted from <http://blog.thearc.org/2016/04/06/mislabeled-sex-offender-kelmar-familys-fight-justice-2/>

My name is Brian Kelmar, and I am the father of a 24 year old son who has autism and auditory and sensory processing disabilities. Our nightmare began almost six years ago, right after my son graduated high school. It's a case of the "perfect storm" that resulted in my son being punished and treated as an outcast in our community and in society.

Do words like "trusting, bullied, eager to please, and not understanding social situations" sound familiar? These words describe my son and how he interacts and/or experiences the world around him. Like others with autism, he had few friends growing up, let alone a girlfriend. That core need for friendship hasn't changed. He continues to long to fit in and feel included, and have friends in his life that he can talk to. So, when a female friend of my younger son started texting my son, he was so happy that he found someone nice to talk to.

The girl's texts started innocently enough with just small talk. The communication began when he was away at a college summer orientation where he was learning about the autism program he was to begin in the fall. The texting from her soon became very sexually aggressive, and he did not understand what the texts were about. He answered her questions with short words or answers, such as "like", "what", "ok", and "huh"? She pointed out to him, "you really don't understand what I am talking about" in regards to her sexual statements like "friends with benefits" and "hooking up," along with more graphic content which he did not understand. When reading the back and forth texting, it's clear to anyone reading these messages that they were going right over my son's head.

After he returned from orientation, she repeatedly began asking him to meet with her. He had no idea of how to handle her sexually aggressive messages, and he certainly didn't foresee what would happen next. When he met her in person, she became very sexually aggressive. Like other people with autism and sensory issues, he can easily become overwhelmed and shut down, similar to a computer that has too many programs open at the same time. This is exactly what happened during her sexual advances. When his mind "rebooted" and his thought process reengaged, he told her to stop. She did and he took her home.

That same evening the police came to our house in the middle of the night. Since the front door is closest to my son's room, he answered it. Not understanding the situation and thinking the girl was in trouble because she was the aggressive one, he answered their questions before I got to the door. The police took him to jail for two days until I could get him released on \$100,000 bail. In an instant, my son's life was changed forever.

My son and our family entered a criminal justice system that we had no idea how to maneuver, and a system that had no idea about autism. Our lawyer had no experience with autism or working with people with disabilities. We were told by the attorney that the only option was to plea bargain. Later I discovered that is how most cases are resolved, through plea bargaining (experts estimate that 90 to 95 percent of both federal and state cases are resolved through plea bargaining).

During the sentencing phase, the judge heard testimony from the court appointed forensic

psychologist with comments like “*It was the alleged victim that was grooming him for a sexual encounter*” “*He did not understand the situation*” “*She was the aggressor*”

These statements were all true based on the evidence of the text messages. The judge understood the situation, and gave my son a ten year suspended sentence. We never had any written plea bargain agreement. Then he was sentenced to 10 years probation. What we did not find out until after the sentencing was that due to the way the law was written, he would not only be on the sex offender registry, ***but he would be put on the violent sexual predator list for life.***

This was absolutely devastating and the consequences last a lifetime. This punishment will limit his ability to be employed, where he or our family can live, where he can travel to visit family members or even his future family (if they are under 18). He can’t even travel to see his own grandmothers now because of the laws affecting travel between states. This whole experience has been like a slow, agonizing psychological death sentence for him, and for our entire family.

Our hope is that other people with intellectual and developmental disabilities (I/DD) and their families can learn from our experience. Here are some lessons learned:

1. Never let your child (regardless of age) speak to authorities without you or another advocate and a lawyer present – no matter what. While there are various organizations like The Arc’s National Center on Criminal Justice and Disability® (NCCJD) and some state agencies which can step in and mitigate the situation, the best scenario is to ensure the person’s rights are protected during questioning.

2. Contact [NCCJD](#) which can provide assistance in cases like this, and can also provide quality, effective training for criminal justice professionals in your state. You will often find that many law enforcement, attorneys and other criminal justice professionals in the criminal justice system have had no training on I/DD. Through NCCJD’s information and referral and technical assistance services, their staff can work with your local chapter of The Arc and other community or state agencies to provide practical solutions that avoid destroying people’s lives before the snowball effect of the criminal justice system starts rolling.

3. If at all possible, hire a lawyer who has experience/expertise in both the specific crime specialty (i.e., sex offenses) and defending people with I/DD. Since few attorneys have this experience, at the very least, he or she should be open to learning more about disabilities and working with NCCJD and other advocacy organizations to provide the best defense possible.

4. Finally, never agree to a plea bargain until it is written down for your approval and you know all of its consequences before you agree to it.

The sex offender registry laws must take into account a person’s disability so that true justice is served. If you or your family has experienced a similar situation, and are willing to share it, please send your story to NCCJD at NCCJDinfo@thearc.org. It’s time to bring this issue to light, and reveal the real life implications these laws have on people with I/DD and their families. We are well aware that ours is only one story of many, but together – our collective stories have the potential to become the catalyst for nationwide change. *If we don’t speak out, who will?*

People with Developmental Disabilities during Emergencies

If you know and love someone with a developmental disability, you have probably worried about the response they may have during an emergency. Needs and abilities vary greatly from person to person, but people with developmental disabilities are more likely to need help during an emergency. It may be assistance identifying the emergency and dialing 911, some people are overwhelmed by sirens and lights and may become upset or try to hide, and some individuals are scared of people in uniform.

Knowing that this is a very real and valid concern for so many of our families, the beginning of this guide focuses on things you can do to promote positive interactions with emergency services, first responders, and police. With planning, practice, and awareness, you can do so much to ensure future contacts during any sort of emergency are successful and safe.

People with Developmental Disabilities in Our Jails: A Big Problem

Unfortunately, not all negative interactions are preventable. Sometimes things go wrong and we need to know how to pick ourselves up and move forward. In recent years, we have seen a consistent rise in inquiries about people with DD becoming caught up in the criminal justice system, most often due to a manifestation of their disability. This has been a horrifying new frontier for the people we serve and we have found ourselves unprepared. This guide is one step we are taking to help manage this crisis.

The numbers of people with developmental disabilities in jails is high. **People with developmental disabilities comprise 2-3% of the total US population, but between 4-10% of the population in detention centers, with the highest concentrations in juvenile facilities.**¹

Anecdotally, we have seen a particular rise in criminal justice issues for people on the autism spectrum. This almost always seems to stem from the disability. For example, a person is exhibiting some behaviors a passerby thinks is unusual, so they call the police. The police witness the behaviors and challenge the person on what they're doing. Someone with a developmental disability is often not able to explain what they are doing and why and can be frightened by the police. Confusion, arguments, and physical struggles can result and we find ourselves in a position where someone whose behavior was a totally innocent action has resulted in them being charged, arrested, and put through the courts.

It is important to know that despite the very high numbers of people with DD in our justice system, people with developmental disabilities are even more likely to become victims of crimes than the typical population. In fact, people with DD are between 4-10 times more likely to be victimized than someone without a developmental disability.²

¹ <http://www.thearc.org/what-we-do/resources/fact-sheets/criminal-justice>

² <http://www.thearc.org/what-we-do/resources/fact-sheets/criminal-justice>

How did the Use of Jails for People with Developmental Disabilities Get So Out of Hand?

There is no evidence that people with developmental disabilities are more likely to commit crimes than peers without disabilities, so why do we see such disproportionate numbers of people with DD arrested and in jail?

- Defendants or suspects with DD often display poor judgement and self-preservation skills.
- People with DD may feel embarrassed because of their disability and may try to hide it.
- People with DD often nod or say yes or use contextual clues to show they are understanding what is explained and asked, even though they are not truly able to follow the conversation.
- People with DD may try to “fit in” with people without disabilities and be easily persuaded or bullied into partaking in criminal activity.
- People with DD have a difficult time processing information as quickly as it may be requested from the police and may experience a fight or flight response out of fear.
- People with DD can be eager to please and try to tell people what they think they would like to hear, including giving confessions for crimes they did not commit.
- People with DD can struggle to read social cues and understand unspoken rules or subtleties.
- People with DD can have unusual behaviors that draw suspicion upon them.
- People with DD may freeze, run, or react poorly when overwhelmed or overstimulated.
- People with DD may better identify with children who have a similar intellectual ability and not understand the consequences of sexual acts, friendships, or child pornography, as the child is seen as an equal.
- Virginia leads the nation in referring students to law enforcement for school-based actions at three times the national average.³
- The state disorderly conduct statute makes it a criminal offense for a student to disrupt instruction during school by causing “inconvenience or annoyance,” even when that behavior is a clear and documented manifestation of a disability.

We can then create a cycle familiar to many in the justice system. People with DD are coerced into committing a crime or confessing to a crime they did not commit. Once in jail, they are significantly more likely to be victimized by other inmates and do not receive supports related to their disability. This can result in negative behaviors while in jail or exacerbation and development of mental health needs or substance abuse issues. People have a harder time showing they have been “rehabilitated,” because they have not been due to a lack of supports or lack of initial criminal intent and have a more difficult time being released. No mandated supports exist related to the disability once people leave jails, leaving people with DD incredibly vulnerable to entering the justice system again and again.

³ <https://www.linkedin.com/pulse/project-save-childhood-need-improve-school-climate-virginia-hiznay?trk=mp-author-card>

Community Services and Supports

This guide will share information about community-based resources to help people with disabilities. Once people with developmental disabilities leave the public school system, either at age 22 when they age out or earlier when they graduate, there are NO mandated public services and supports available. Public services that do exist often have long waiting lists and limited support options. A lack of supports can quickly lead to entanglement in the justice system. Strong community supports, on the other hand, can result in happy, healthy lives in integrated communities. Knowing the services available to help prevent negative situations and to leverage if something unfortunate happens are key to building a positive and safe future for people with developmental disabilities.

BIG TAKEAWAY

There are large numbers of people with developmental disabilities in our jails. The reasons vary, but parents and family are almost always surprised that things went wrong. The best thing you can do is work to prevent these sorts of issues, using tools like this guide.

Developmental Disabilities and the Importance of Diagnosis

Having a clear diagnosis of a developmental disability is key to accessing services, preventative planning, and formulating a legal defense. In this section, we'll review what the state of Virginia considers a developmental disability, documents you may already have with a diagnosis, and information on what should be in a diagnostic evaluation.

For this section and throughout the book, we are using the term "developmental disability" because developmental disabilities include intellectual disabilities, as well as individuals who may have had a disability onset a few years later and those who may have slightly higher IQs while still exhibiting all the hallmarks of the cognitive disability. In 2015, Virginia adapted a state definition of Developmental Disability and that appears below. Note that it does not have a specific IQ maximum or minimum requirement.

Virginia State Definition of Developmental Disability

See: Virginia Code §37.2-100

"Developmental disability" means a severe, chronic disability of an individual that

- (i) is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness;
- (ii) is manifested before the individual reaches 22 years of age;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency; and
- (v) reflects the individual's need for a combination and sequence of special interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are 2 of 3 individually planned and coordinated.

An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual, without services and supports, has a high probability of meeting those criteria later in life."

Proof of a developmental disability can be obtained through a full scale IQ AND diagnosis on a psychological exam. In Virginia, this is most commonly done by a licensed psychologist in the school system (for children still in school) or private psychologists (for adults). The psychologist should be knowledgeable about and experienced with evaluating people with developmental disabilities. See Appendix IX for a list of some of the Northern Virginia providers who can offer this testing.

There is no mandate for testing or records maintenance, so it is entirely possible someone who has had a developmental disability their entire life will only first be diagnosed when encountering a crisis, such as an interaction with the court system. In this case, it is important to show the disability onset during the developmental period with documentation from the

doctor, school, or other professionals that have interacted with the person before age 22 and noticed issues with processing, adaptive skills, cognition, etc.

Documents that May Confirm a Developmental Disability

Some of the best documents to locate and examine to see if a developmental disability has already been diagnosed are listed below. Look for these documents and be sure to get releases to allow these documents to be shared with you if you are not the person with a disability or his or her legal guardian.

- School records, including Individualized Education Plans (IEPs) or 504 Plans
- Determinations from Social Security of a disability including receipt of Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)
- Psychological evaluations, IQ tests, or other screening tools and tests
- A Special Needs Trust that may reference other documents
- Guardianship or conservatorship paperwork

Examining IQ Scores and Adaptive Behavior

IQ scores, like any testing mechanism, are not perfect, yet they are heavily relied upon when diagnosing intellectual disabilities and sometimes developmental disabilities. As previously mentioned, Virginia historically used an IQ ceiling of 70 as a hard cut off for a diagnosis of an intellectual disability, though IQ tests have a “Standard Error of Measurement” of plus or minus 5 points. That means someone with an IQ of up to 75 can have an intellectual disability. The vast majority of people with intellectual disabilities have a mild intellectual disability, usually shown by a score of 52-70 on IQ tests. This is often where a criminal defendant will score.

IQ scores can vary over time. IQs measure people with developmental disabilities against same aged peers, and for many people, that gap widens with age. Thus, mental age and chronological age can be significantly out of sync.

There is no ceiling for developmental disabilities and some people with DD have genius IQs, but can lack the basic life and adaptive skills they need to function with independence. You will need to look beyond IQ, for a full evaluation and diagnosis, to see these needs.

Adaptive behavior evaluations study how people are able to care for themselves and interact with others in the course of normal life. They look beyond abstract controlled testing and reasoning and focus on interviews with the individual and people in their life. They are a much better snapshot of the manifestation of the disability in everyday situations.

It is common for people with developmental disabilities to struggle picking up the adaptive behavior and social cues most people come to understand naturally as they grow into adulthood. Sometimes people exhibit great strengths in one area and large deficits in another.

Examples of areas assessed by adaptive behavior measures and possible affected areas are below.

Conceptual Skills- Can the person read, write and understand language; can the person understand the concept of money and value and work with it; can the person truly self-direct choices?

Social Skills- How well does the person relate to peers (and who do they believe their peers are?), family and others; can the person be responsible for themselves; what is the person's level of self-esteem; is the person naïve; can the person understand and follow rules without supports; can the person understand laws; does the person have an ability to prevent themselves from being victimized?

Practical Skills- How well does the individual manage activities of daily living (e.g., cooking, cleaning, hygiene); does the person possess occupational skills; can the person maintain a safe environment for themselves?

If you are seeking an analysis of adaptive behavior, ensure the psychologist understands the need to highlight the following:

- If the person is easily coerced by peers or authority figures
- If the person has issues with verbal processing that result in them appearing to understand information, but not having any real understanding when questioned about that information
- If the person has behaviors or other manifestations of their disability that can directly or indirectly cause violent outbursts
- If the person understands and can articulate their disability or they try to hide their disability
- If the person has issues with short or long term memory

BIG TAKEAWAY

You must have a clear, thorough diagnosis and assessment on hand to access support services, effectively prevent crises, and show the impact of the disability on actions in the event something goes wrong.

Making a Safety Plan

The very best thing you can do to manage dangerous situations and interactions with the justice system is to prevent them from happening. This starts with an assessment by you, the person with a developmental disability, and other people who know the person with a disability well. Doing this as a team is key. Everyone will know different strengths and challenges for the person, how well the person does in different situations, and what some temptations or concerns have been in the past. Use the Likely Areas of Concern section below to identify the areas where support may be needed, and combine those documents to make a safety plan. Plan to update it annually at the start of the year.

- Your plan should also include a contact sheet for people like the following:
- Psychiatrist and/or psychologist working with your family member
- Physicians and therapists working with your family member
- Medication names, dosages, purpose
- Health information including allergies, health conditions
- Any history of hospitalization for crisis

Building a Circle of Support

Central to anything that will happen, good or bad, should be a support team “wrapped around” the person with a disability. Teams like this go by many names - circles of support, circles of friends, microboards, personal networks, etc. For consistency, we will use circle of support.

A circle of support is group of people who work together, formally or informally, to foster a life of success alongside a person with a disability. The members should know the person with a disability and be dedicated to their success. Members should be people who the person with a disability trusts and wants to be there. The group can be large or small, but you will want at least a consistent core group of 4-7 people there who communicate on an ongoing basis.

Circle “members” should be balanced in an ideal world. It is good to have some family, friends, people paid to be in the person’s life (e.g., doctors, financial planner, support staff) who have subject matter expertise, people from the community at large (e.g., people from your house of worship, recreation activities, other parents who may or may not have kids with disabilities).

The circle will matter a great deal. It will be a powerful group of people looking out for and supporting the person with a disability. They should see the person routinely. Having a strong community network and group of friends is one of the best ways to deter negative interactions with the justice system. If something ever does go wrong, this group can rally, call in resources, and see the issue through.

Circles are used for lots of things and there is more information on them in Appendix XI.

BIG TAKEAWAY

You can't plan for and prevent everything, but start with what you know may be an issue and work from there. Having anything at all in hand is better than nothing in the event of an emergency.

Identify Likely Areas of Concern

You and your circle should be thinking about the safety plan from multiple sides—is the person likely to wander, to commit a crime, to be a victim, to be alone and need to ask for help, etc. Let’s take a variety of common situations one by one and examine some ways you can plan to prevent negative incidents.

Possible Police Interactions

Interactions with the police can happen for a number of reasons. Sometimes a person with a disability is doing something perfectly innocent, but his or her mannerisms may alarm someone. Families have also described situations where behaviors traditionally associated with autism were perceived by police to be indicative of someone on drugs.

Practice asking for a phone call if arrested, and memorizing that number. Cell phones are confiscated after arrest.

The law applies to everyone, so someone with a developmental disability is held to the same legal standards of conduct as everyone else, no matter their level of ability and regardless of any legal authority (e.g., guardianship) you may have put in place.

Here are good ways to promote positive interactions with police.

1. Have a “911 Flag sheet.” Anyone can create a sheet with core information on it about how to recognize and respond to a person with a disability. You can take it to your local police precinct and ask that they keep it and flag the numbers, names, and addresses listed so that if a call originates from/about one of the listed places, police are aware of who may be involved and how to best proceed. Update the sheet often. Take the person with a disability to the police office when you go and help them become familiar with some of the local officers and people in uniform.

Sample 911 Flag Sheet

Name: Dennis the Menace

Nickname or Preferred names: Dennis

Age: Include age and when this was last updated

Description: Include a general physical description including size, strength, clothing preferences, etc.

Address(es): Include home address, work, school, places frequently visited

Number(s): Include home, cell phone contacts for family and circle of support, numbers of places the person attends daily or frequently

Places you may see me: Lists of places the person likes to go, places they visit on a routine basis, and transportation options available to them (e.g., Metrocard, Uber)



If you see me, you should know: This is a good place to share a diagnosis(es). Talk about what you expect may happen and how to respond.

Example: I have autism. I sometimes yell, flap my arms, and run away from my parents or caregivers. I do not like to be touched. If you see me, do not touch me or come closer than 4' from me. I do not like loud noises. Please do not use a siren or yell. I don't like police uniforms. Try to look casual or send someone in casual dress.

I love Mickey Mouse. If you find me alone, you can show me a Mickey video on your phone. Tell me that you'll call my mom to come help me and we'll wait together until she arrives. Use a really calm voice. Look at me, but don't expect me to make eye contact with you.

I have a behavior plan (attached). REACH Crisis Services know me and you can call them at 855-897-8278 if you need crisis intervention help.

2. Visit your local police station and talk to police officers you see in the community alongside the person with a disability. Anyone can ask to visit or tour a local police office. Let the person with a disability become used to seeing people in uniform, hearing the sound of calls coming in through the radio system, and see police acting calmly and causally. Introduce the person to police officers in the street and at community events. The police do a great deal to have a public presence and want to know community members. Talk about how different officers do different jobs or may wear different uniforms.
3. Practice. Identify the ways you think your loved one is most likely to interact with the police—questioning for unusual behaviors, wandering, committing a crime, feeling scared, etc. and write out full scripts for how you hope the interaction would go. Practice by role playing how the person can ask for help, raise hands, stay safe, and identify themselves. Practice at least every 2-3 months.
4. Get an ID card that indicate there is a disability present. Virginia's DMV allows anyone of any age to get an ID card. You can choose to have an indicator on the card that denotes an intellectual or developmental disability, autism, and other needs. Police are trained to look for these codes on licenses.
5. Know your local programs. Some localities have special programs to promote safe police interactions.

In 2015, Fairfax launched a program called [Diversion First](#), based on a national jail diversion model. Diversion First is focused on alternatives to incarceration for people with mental illness, developmental disabilities, or both, who have come into contact with the justice system for low level crimes or other offenses. Diversion First has trained personnel and services at every stage of the process, from initial police contact to jails. It is never too late to ask that someone (e.g., judge, clerk, police officer) trained in Diversion First work on the case. The program is aimed at preventing repeated encounters with the justice system in a community-based cost effective way. There are several components to the program:

- **Merrifield Crisis Response Center (MCRC)**
This is a 24/7 crisis and assessment site where police can transfer custody of non-violent offenders for screening of disability or mental health needs. Officers working here are trained in Crisis Intervention Training. The Center aims to stabilize individuals and prevent them from heading to jail.
- **Crisis Intervention Team (CIT) Training**
This training is available to all Fairfax law enforcement bodies and entails 40+ hours of additional certified training. **Anyone calling emergency services can request a CIT officer as they are better equipped to identify and work with people with developmental disabilities.** You can also request a CIT trained officer within the judicial system.
- **Mobile Crisis Unit**
This team can mobilize around the county and meet individuals in crisis where they are to provide assessment and supports.
- **Mental Health Docket**
The Diversion First initiative aims to establish a Mental Health Docket in the Fairfax County Court system.

The Arc of Loudoun, Paxton Campus has worked with Loudoun police to create a program called [PILE: Positive Interactions with Law Enforcement](#). The program has police officers visit students at their campus and adults working there. Officers can ask frank questions and learn about the needs of people with DD. To learn more, visit <http://www.paxtoncampus.org/>

6. Know [common crimes](#) and do what you can from preventing them from happening. Examples are below.

Common Crime for People with DD	Possible Preventative Measures
<p>Petty theft - This can happen especially when the person with DD does not understand why they cannot have something immediately or is fearful they will never be able to obtain something they want. People with developmental disabilities may struggle to understand they are stealing if they are taking something from family, friends, neighbors, etc., with whom they feel they have a friendly relationship.</p>	<ul style="list-style-type: none"> • Practice supports with financial literacy. Work to ensure the person with a developmental disability feels they have control over their money and can save and work to earn the things they want. • Provide verbal reminders and reinforcement about what is sharing versus taking.
<p>Grand larceny - Common in school and other settings now that the value of many common goods (e.g., sneakers, smart phones) are over \$200. Sometimes people with developmental disabilities are under the mistaken impression they were allowed to borrow something.</p>	<ul style="list-style-type: none"> • Practice supports with financial literacy. Work to ensure the person with a developmental disability feels they have control over their money and can save and work to earn the things they want. • Provide verbal reminders and reinforcement about what is sharing versus taking.
<p>Assaulting an Officer and Resisting Arrest - Increasingly we are seeing people with</p>	<ul style="list-style-type: none"> • Use the tactics above to get individuals comfortable with police.

Common Crime for People with DD	Possible Preventative Measures
<p>autism and other developmental disabilities frightened by the police and unable to communicate. They may flap their hands, yell, or otherwise behave in a way perceived as threatening. People may not understand what police are requesting, and therefore they are not able to comply. It is also frequent for someone with autism to be very sensitive to touch and noise and to physically fight back to avoid being touched. This is a manifestation of the disability.</p>	<ul style="list-style-type: none"> ● Practice these interactions and put a 911 flag sheet at your local police department. ● Put an indicator of someone’s disability on their ID and practice having them hand that ID over to someone when asked.
<p>Trespassing - If the person with a disability does have school or other community-based supports, they may end up idling around without help or focus on what to do. They can easily wander into areas they should not go (even with signage up) without understanding this is prohibited.</p>	<ul style="list-style-type: none"> ● Work to put a good support team in place that has a meaningful day planned every day. ● Prevent boredom and promote options and choice on where to go and when. ● Install a GPS option on the phone of the person with a disability to help them navigate safe places to go and times to go there. ● Encourage independent travel training.
<p>Sexual interactions with a minor - People with disabilities are rarely taught sex education in school and often have few opportunities for age appropriate sexual expression. There is a tendency to identify with children as peers as well as a lack of understanding of what is appropriate. “Age discordant sex play” is the term for appropriate sexual behavior with people of inappropriate age.</p>	<ul style="list-style-type: none"> ● Provide (or ensure someone provides) cognitively appropriate sex and relationship education. Don’t rely on the schools to do this and talk in clear, concrete terms. ● Talk about healthy relationships and how to show and share affection. ● Discuss who can give consent, how, and why. ● Have an open door policy to talk about issues or questions.
<p>Child pornography - Many people with disabilities have difficulty distinguishing between a young 20-something adult and a teenager and may not understand subtle wording distinguishing the two. It is also common for people with DD to say they more closely identify with small children and that the idea of children having adult experiences may not seem as odd as it does to many people. Increasingly we are hearing that “something just popped up on my computer.” This is a growing concern as more work and life skill learning is done online. The book <i>The Autism Spectrum, Sexuality, and the Law</i> describes some of the</p>	<ul style="list-style-type: none"> ● This crime has risen quickly in the era of the internet. Talk about phone and internet usage. ● Put up firewalls if needed. ● If needed, check on activity on a routine basis by checking site and search histories. Avoid doing this as a means to violate privacy, but talk with the person about what you’re doing and why. Give examples of good and bad sites. ● Provide (or ensure someone provides) cognitively appropriate sex education. Don’t rely on the schools to do this and talk in clear, concrete terms. ● Talk about healthy relationships and how to show and share affection. Have an open door policy to talk about issues or questions.

Common Crime for People with DD	Possible Preventative Measures
issues associated with autism and a draw to child pornography.	

BIG TAKEAWAY

Though it may be difficult, having frank conversations about right/wrong, money, and sex and relationships is critical to helping prevent possible criminal interactions. Find teaching moments in everyday life and don't rely on others or one time conversations to be enough.

Wandering

Casually wandering away, eloping, or becoming lost are fairly common needs in the DD community. This is a clear immediate safety concern and can open the door to other issues, like the person being mistaken for someone doing something wrong who is then approached by police.

There are a lot of strategies to manage this concern.

1. Have a wandering protocol in place. Everyone who is part of the person's life on an ongoing basis should have a copy. The protocol should include the following, much like the 911 flag sheet above which can be used for this purpose as well.
 - a. The person's name, age, and general physical description
 - b. A recent photograph
 - c. A list of who to contact as soon as the person is missing or suspected missing
 - d. Numbers to call if the person is found including family, support staff, neighbors, circle members, police
 - e. Lists of places the person likes to go, places they have wandered in the past, and transportation options available to them (e.g., Metrocard, Uber)
 - f. What to do if the person is seen. This is critical. Should the person be approached or not? If yes, how? What are some soothing words to say? Is there a video or song that could be shown on a Smart Phone or similar device to comfort the person? Is there anything that should NOT happen—loud noises, requests to move locations, demands to leave, etc.?
 - g. Other tips and tricks for those who may encounter the person. This can include ideas like engaging the person in a conversation about the person's favorite topic.
2. If the person consistently wanders or elopes to a certain place, try to build in routine daily or weekly time there. Support them in learning that they can go there with supports often and that they can request trips there without having to go alone.
3. Use your networks and neighborhood. If you have people you trust in your neighborhood and community, ensure that they have contact information for you and members of the circle of support to contact if they see the person alone or wandering.
4. If the person consistently wanders or elopes, you may consider having keypad locks put on the inside of doors leading outside. These require that a code be entered to exit. You can have them wired to a security system (if you have one) to automatically unlock if a fire or other alarm goes off. These systems may be covered under the Environmental Modifications services of the Medicaid Waiver. If you have a Waiver or want to learn more about this, see Appendix XII.
5. [Project Lifesaver](#) is a national recovery program with a phenomenal success rate. Participants in the program wear a bracelet that resembles a watch or an anklet with a radio transmitter inside. If someone is missing, specially trained officers start searching for the radio signal at the last location the person was seen. 95% of people are found inside of 30 minutes. The batteries are updated monthly by local sheriff's departments which is a great way to practice positive interactions with law enforcement. This is a service that can be covered with private pay (about \$25/month) or Medicaid Waiver.

Dangerous Behaviors

It is not uncommon for people with developmental disabilities to have mental health needs and/or behavioral challenges that can pose a disturbance or a danger to themselves or others. Below are some ways to safely support someone with these needs.

1. Create a flag sheet as referenced above in the section on police interactions.
2. Have a really good behavior supports plan in place. If there is any history of behavioral needs, work with a good behaviorist (some listed in Appendix X) to identify the source of the behavior. All behavior is used to communicate something and good behavior analysts should work with the person to identify behavioral triggers and come up with a plan to reduce them by giving the person another way to communicate the need or helping them to meet the need. In school settings, students should have a Functional Behavioral Analysis (FBA) to assess the person and a Behavior Intervention Plan (BIP) to help everyone who works with the student consistently know how to support the person to prevent and deescalate behaviors as well as protocols for how to support the person if the behaviors increase in intensity. In the adult services world, these plans are simply known as “Behavior Plans.” They should be reevaluated often and updated. Everyone working with the person should apply the plan consistently for it to work.
3. Virginia has a free crisis response team for people with disabilities created in compliance with a 2012 settlement agreement with the Department of Justice. People may call and meet with the crisis teams proactively to set up a profile and have the person assessed. Then, in the event of an emergency, the crisis team can be contacted to come onsite and help de-escalate the behavior.

In Northern Virginia, you can reach the adult team, called REACH at (855) 897-8278, <http://www.dbhds.virginia.gov/individuals-and-families/developmental-disabilities/crisis-services>

In Northern Virginia, you can reach the team for children under 18, called CR2 at 571-364-7390, <http://cr2crisis.com/>

Calling 911

If the person with a disability lives alone or is alone for frequent periods of time, practice identifying emergencies and responding appropriately. Use the following strategies to plan for safety.

1. Use a 911 Flag sheet as described in the section above on positive police interactions so that calls originating from the person's home are connected to their flag sheet and 911 operators are prepared.
2. Use a sample script and practice at home. Think about things likely to happen- a fire, a caregiver who passes away, injuries, etc. Write out a script that would walk the person through all the phases of these events, who would talk to them, what they should say, who to ask for help, etc.
3. Practice with the experts. If you call your local non-emergency police line, they are likely going to be willing to allow the person with a disability to make a practice call to 911 so they can hear what will happen if/when they really do call. They can practice reading their script and talking to an operator. Ask to do this as often as needed. You can also drive by and visit ambulance and fire stations. Ask to tour, see the lights, and hear the sirens. Practice talking to the firefighters and EMTs. Have the people at your local station get to know the person with a disability by name and face.
4. Pack a "go bag." If you think an emergency may happen that could displace the person, have an emergency "go bag" packed so they have everything they need in one place. This could include phone chargers, photos, emergency contacts, IDs, clothing, toiletries, soothing items, and other mementos. Practice remembering where it is and picking it up to leave.
5. You can order stickers to put on windows of the home to alert fire and rescue personnel that someone vulnerable is inside who may resist help or not respond to commands. You can buy stickers like this at Amazon and other retailers (example- https://smile.amazon.com/CafePress-Emergency-Warning-Sticker-Rectangle/dp/B00PCRLPB4/ref=pd_sim_263_4?ie=UTF8&psc=1&refRID=2VPWV304X3RV6JJWVKWP)
6. Fairfax County's Fire and Rescue Department has a "Yellow Dot Program" that alerts first responders that there is someone vulnerable in a car after a vehicle crash or other incident. You can visit any local Fairfax Fire Station for a "Yellow Dot Kit." They will provide you with a booklet where you can write important information including a photo, disabilities, medical conditions, medications, etc. That booklet is stored in your glovebox. The kit also comes with a yellow dot sticker you place in the lower left corner of the car's rear windshield to let first responders know to look for the booklet. Read more here- <http://www.fairfaxcounty.gov/news2/yellow-dot-program-could-save-your-life/>

One Family's 911 Script

Sharon and Conner are amazing advocates. Sharon developed this 911 call script for Conner. You can use it as a basis for yours. Follow their efforts online at <https://www.facebook.com/conquerforconner/>

"If Mommy Doesn't Wake Up"—Sharon's instructions to Conner for 911 calls

SCRIPT

Instructions from Love-

Conner, if Mommy does not wake up and you cannot wake me up, do not panic. You will be fine. Call 911 like we practiced...you know how. Remember to tell them your name and that you need help Mommy is not waking up. Tell them your address and that you are Autistic. They will help you. Ask them to stay on the phone with you and tell you when the ambulance is at the door. Unlock the door. You can open the door and tell them they can come in. You can ride with them in the ambulance-they will help you. They will pick Mommy up and put me on like a portable bed. This is ok. They are professionals and know their job. They will carry Mommy out to the ambulance.

They will let you sit in the ambulance and tell you where. You may not be able to hold Mom's hand as they may be doing their doctor stuff to Mommy. That is ok as they are conducting the miracle of medicine. Just like Disney Magic!

Call the names and numbers that mommy has programmed on your phone. If it is too hard ask them to help you. Grab the bag that is with this note. Remember the bag has helpful tools for you to get through this. You have your phone charger. You have cash so you can buy a snack. You have your favorite writing pad. All of your favorite pictures and stories are on your phone. You have your ear plugs. You can play on your phone as much as you want...remember you have the charge-ask to sit by a plug.

You will be fine just like we talked about. Mommy will always be with you in your heart and soul. I will be a part of you guiding and protecting you! You did a good job. I am proud of you. Now read my next instructions and I left a message just for you to read when you feel like you need to hear Mom. Most importantly, Mommy loves you. You will have a great Magical life just like we talked about. I love you past the other side of the rainbow and to the moon and back. You are the best thing that ever happened to me. Mommy and Conner Forever- You will always be my Special Love!

OTHER INSTRUCTIONS

In the bag (in addition to cash/phone plug mentioned above) include whatever is their favorite thing. A stuff animal, a book, toy, blanket... anything. I have extras that always stay in the bag. Conner's favorite things right now are his phone where he keeps his favorite pictures, where he writes his Facebook post and where he can go on-line to all his favorite sites. I also have a pair of Mickey Ears because they give Conner strength and an autograph book signed by all of his favorite Disney Princesses and Characters.

I also have a note for the ambulance people and a note for the hospital attendant. Write what calms your child and ways to connect with your child. In my case – talk about Disney, Dancing with the Stars, talk about his post or Conner's Law. I wanted Conner to feel as comfortable as possible so the best thing I can do is set up a familiar scenario as possible. I ask that they keep

Conner close to me and that someone supervises him until a family member or close friend from the list can get to him.

The people on the list are instructed to contact the hospital staff to ensure that Conner is being cared for until they get there and they will stay in contact with him until they arrive. Conner knows he will go home with the person but he will be back to see Mommy and will always be aware of what is going on. My family and friends know to text this information to Conner so he can text back his feelings.

I remind Conner to put his shoes on and grab his favorite jacket.

YOUR SUPPORT TEAM

Make sure whomever you program into the phones (I have my personal, his personal and the home phone programmed) that you speak with these people so they know and understand your wishes.

Go over the plan with them once they learn it as much as you think is necessary. Conner and I do the plan once a month now. We did it every night before his prayers for months when I first wrote it.

Contact non-emergency number for 911 and explain what you would like to do to get it set up or go into your local Police department and explain in person.

In my plan I wrote it up like I am speaking directly to him including all the complements and encouragement I would give.

Think about a travel plan or a plan at Grandparents house if they go there by themselves.

The reason why Conner is trained to contact 911 but has called family/friends per my request is I want 911 only if I am not awake, as I know in this last case where I fainted that they would of kept me over night for observations and I did not want to put Conner through all of that if it is not totally necessary. When is the right time – is up to you and your plan!

For me this put my mind so much more at ease. The worry of what will happen to Conner if I do not wake up is not a plan. It is something concrete that Conner can follow. I knew this would help Conner. He has a script – he has a plan! Conner does not like to speak on the phone but because this is a plan that he has practiced and learned he does his script and he can do it and do it well.

He will get through the emergency in a calm focused mode because of this plan. This plan for me has proven himself – twice!

BIG TAKEAWAY

When you sit down to come up with a preventative plan for a variety of circumstances, just take one thing at a time. Write down what you can think of and save it. Your resource library will grow overtime. Plan to update the documents every year at the same time to ensure they stay useful.

School Aged Children and Justice Issues

A 2015 report from the Center for Public Integrity ranked Virginia worst in the country for the “school to prison pipeline,” the disturbing trend of having school-based behaviors referred to law enforcement and prosecuted.⁴ Significant portions of arrested juveniles are younger than teenage years.⁵

If your child has a disability or you suspect he or she may, ask in writing for testing to confirm the diagnosis and disability. Get an Individualized Education Plan (IEP) in place to ensure your student receives free and appropriate public education that meets all of their educational needs, including school placement and behavioral needs. For more on the Special Education system, refer to our free guide, Transition POINTS: Education at <https://thearcofnova.org/programs/transition/getting-special-education/>

Students often end up routed through the justice system directly from school for behavioral needs. Ensure that if your student has any behavior needs requiring accommodations or support that a Functional Behavioral Assessment (FBA) is done. All behaviors are communicating something—pain, fear, boredom, frustration, or desire. The FBA should work to show causes of behaviors and how behaviors manifest themselves in a variety of situations. This should lead to the development of a Behavioral Intervention Plan (BIP). The BIP should guide anyone who works with your student on how to support them in avoiding, diverting, and calming behaviors. It should include rewards and recognition of the behaviors, not simply instructions to mask or “manage them.” We need to give the person other ways to express needs and get what the person wants.

BIG TAKEAWAY

Children can be, and are, arrested in school. School statements can be used against them in court. Have a strong IEP in place, a committed school team on board, and teach your child to ask for you to be called before they ever give statements of self-incrimination. You have the right to us an attorney, even in school settings.

Laws, Mandates, and Rights

All children are entitled to free and appropriate public education per a federal law called the Individuals with Disabilities Education Act (IDEA). For children with disabilities, the way in which

⁴ <https://www.publicintegrity.org/2015/04/10/17089/virginia-tops-nation-sending-students-cops-courts-where-does-your-state-rank>

⁵

<http://www.djj.virginia.gov/pdf/admin/Profiles%20of%20Committed%20Juveniles,%20Fiscal%20Years%202004-2013.pdf>

this is delivered is outlined in the IEP. Ensure the IEP team is the right team—people who care about the success of the student and are willing to work to make it better. IEPs don't just determine goals for the year. They decide who will be involved in working with your child, the setting (within the school or which school) where services will be delivered, and reflect your child's needs and abilities.

Work hard to ensure the IEP is setting the right tone and wrapping supports around your child to try and prevent situations where he or she might feel overwhelmed, bored, or are otherwise put in situations likely to spark behavioral outbursts. This should be included in the Present Level of Performance (PLOP) and/or the IEP. Causes of behaviors and likely behaviors must be addressed within the IEP, not just inside a BIP. It is still important to ensure a BIP is in place to get the entire team working together on ensuring the person has their needs met and negative behaviors are prevented or limited.

Some of the biggest barriers to a successful life in the community are communication, anxiety, and social needs. Ensure these needs are a focus of the IEP team and active work is being done to address these needs to prevent setting your loved one up for trouble outside of school.

Seclusion and restraint are still legal and frequently used, disproportionately on students with disabilities. Studies consistently show a rise in behaviors, fear, and other traumatic outcomes as a result of these practices. Once they start, a cycle can quickly develop where the student is fearful of going to school or upset more easily, exhibits a disruptive behavior, and is secluded or restrained again. This paves a path towards escalated interactions and worse. Be on the lookout for changes in behavior, especially refusal to attend school. Rule out medical causes, then look to school issues as a cause.

Virginia's Disorderly Conduct Statute makes it a crime for a student to disrupt instruction in school by "causing inconvenience or annoyance." This remains the case even if the "disruptive behavior" is a clear and known manifestation of the disability and even if the behavior was set off by someone without proper training unintentionally escalating the situation.

Virginia code mandates that school behavior suspected of being criminal in nature (even when it is directly related to the disability and is expected based upon the FBA) be reported to law enforcement. Students may have an incident at school and be asked to sit down and write what happened. That statement can be made without parental notice or involvement, then later be turned over to the police and used as evidence to prosecute the student in court.

A long-term suspension (10+ days) can be appealed and you can work with an attorney to do it. You want to ask for a Manifestation Determination Review (MDR) to explore links between the disability and suspending behavior. Your child can evoke their Fifth Amendment right against self-incrimination.

Know your rights as a parent. Have a strong IEP, a good FBA, and a BIP implemented. Help your child understand his or her rights. Children can ask for you (and should) if they feel they are being interrogated. They do not have to write or sign statements of self-incrimination; they always maintain Fifth Amendment rights. If they do not understand what is going on, they can and should ask for help to the best of their ability.

You can be forced to testify against your own child in court. Be careful in planning what you discuss and talk with an attorney about how to proceed if you're moving towards criminal charges.

Special Education Advocates and Attorneys

Anyone is welcome to hire a Special Education Advocate or Attorney at any time to help them navigate the school and IEP process. Special education advocates and attorneys are privately hired support persons for those who feel they need assistance navigating the Special Education process. You can hire these individuals to consult on questions, attend IEP meetings, research and navigate on your behalf, and answer questions about local, federal, and state requirements for Special Education. Attorneys are able to bring a lawsuit against the school if you determine that is the appropriate course of action. Their services are generally more costly than those of advocates.

Training varies widely and you should ask. Any attorney should have completed law school and passed the bar in this state in order to operate as an attorney. Their legal background may or may not all be involved with Special Education. Advocates are not certified and have no formal training that is mandated. They are not subject to attorney/client privilege like attorneys. Be sure to ask about their background in general and in working with cases like yours. For a list of attorneys and advocates, see Appendix VII.

Ways to Learn about Educational Rights

If your child is in Special Education, it will be of great benefit to you and the child if you are able to learn more about their rights, your rights, and what to do if you have concerns. Special Education Advocates and Attorneys can help with this. However, they are privately funded and some families do not have the means to pay for their services. There are lots of other ways for you as a parent to become an involved advocate for your child, either by working to find affordable services or becoming a savvy advocate yourself.

Options for doing this include:

- If your child qualifies for free or reduced lunch at school, you likely qualify for legal aid, www.lsnv.org. They may or may not be able to take your particular case.
- The Virginia Office of Protection and Advocacy likes to take cases for people having trouble exercising their rights that will have a broad impact on services for others, www.vopa.state.va.us or 800-552-3962.
- You can ask an attorney or advocate if they have a sliding scale or can take into account any extenuating circumstances. This is a common request, so they are not always going to say yes.
- You can become an educated and savvy advocate for your loved one on your own. Here are some great options to get started:
 - One of our best special education resources is (PEATC.org) is a local non-profit that provides families with information about the IEP process and updates on education law and policy.
 - Wrights Law (www.wrightslaw.com) offers paid advocacy training for parents along with a free e-newsletter and informative website with lots

of hard to find educational information, such details on behavior support in schools.

- The Down Syndrome Association of Northern Virginia often offers free workshops for parents on IEPs. http://www.dsanv.org/base.cgim?template=iep_support
- Go to www.asnv.org, scroll to the bottom in the Connect With Us section and join their Yahoo group to ask questions about the best schools and IEP strategies.
- Residents of Loudon can reach out to Melissa Heifetz for consulting questions, www.paxtoncampus.org.
- Lastly, if your child is in crisis, ask your school social worker about funding in-home services through the Comprehensive Services Act (www.csa.virginia.gov).

BIG TAKEAWAY

Your child has the right to a free, appropriate public education. Ensure those needs are met with a very well done IEP. Have behavior plans in place and don't hesitate to work with an attorney or advocate if you have concerns about educational rights. Decisions made in school settings can be appealed.

Experiencing a Behavioral Crisis

Crises are always scary. As we emphasize in this guide, your best weapon is prevention. However, if you find your loved one in the midst of a rising behavioral or mental health crisis, it is time to get help. Who you call and when will depend on the situation and your loved one. The chart below is meant to help you weigh the benefits and full considerations of a number of possible contacts.

Crisis Resource	Benefits	Considerations
<p>REACH (855-897-8278) - Free, mobile crisis response team for adults (18 years and older) with DD who are experiencing a mental health or behavioral crisis</p>	<ul style="list-style-type: none"> • Mobile Crisis Units • 24/7 crisis hotline • Therapeutic approach to intervention • Community and home-based crisis intervention and stabilization support • A multidisciplinary support team, utilizing a biopsychosocial approach • Emphasizes crisis prevention 	<ul style="list-style-type: none"> • Only for adults 18 years and older • The only NOVA crisis respite home is in Woodbridge and accommodates a maximum of 6 individuals • They do not provide ongoing behavioral supports • They cannot provide hands-on support in the event that behaviors need physical intervention
<p>CR2 (844-N-Crisis) - Free, mobile crisis response team for children (age 17 or younger) with DD experiencing a mental health or behavioral crisis</p>	<ul style="list-style-type: none"> • Rapid mobile response that comes to you • Works to prevent unnecessary hospitalizations and placements outside the home • Available 24/7 • Offers screening and triage • Includes crisis case management • Can provide clinical and psychiatric assessments • Can provide inpatient services if needed • 30-day post discharge support • Care coordination with community resources and professionals • Safety planning 	<ul style="list-style-type: none"> • Only for children 17 or younger • CR2 must leverage existing mental health and other support locations if out of home placement is needed (they do not operate their own crisis respite center) • They do not provide ongoing behavioral supports • This is a relatively new service

Crisis Resource	Benefits	Considerations
<p>Crisis Intervention Trained Police Officer (911) - A police officer specially trained in handling crisis for people with mental health, DD, or substance abuse needs</p>	<ul style="list-style-type: none"> • Community policing model that brings together police, support providers, hospitals, ERs, and families to respond in crisis • Officers have 40 hours of training in CIT • Officers work to build de-escalation skills, use body language, and calmly work with people to get them to accept help • In Fairfax, you can request a “Diversion First” officer who understands CIT and is familiar with the Fairfax crisis response and Diversion First program 	<ul style="list-style-type: none"> • Responders are police officers whose duty and focus is upholding the law • You must request a CIT officer when placing a 911 call • Backup officers may not necessarily be CIT trained • Officers will not know the person or their needs in advance unless you have set up a 911 flag sheet
<p>First responders (911) - standard police, fire, and rescue staff who can respond to an emergency</p>	<ul style="list-style-type: none"> • Able to quickly respond to emergencies • Skilled at First Aid, CPR, mobilizing resources (e.g., to find someone who has wandered) 	<ul style="list-style-type: none"> • These responders may not have any training or experience with people with DD • Responders are used to acting quickly and on instinct. Unless you have set up a 911 Flag sheet or otherwise done outreach, they will not know the person with a disability and their needs. • Disabilities can be mistaken for signs of drug use or disrespect if they are not well understood

<p>Emergency Services Alexandria (703-746-3401) Arlington (703-228-5160) Fairfax (703-573-5679) Loudoun (703-777-0320) Manassas (703-792-7800) Woodbridge (703-792-4900) - County based supports focused on people experiencing a mental health crisis</p>	<ul style="list-style-type: none"> • All counties have phone and in-person (center-based) supports available 24/7 • Offer crisis intervention • Can discuss short and long term voluntary and involuntary commitment • Psychiatric treatment and counseling • Services are free or reduced cost, but no one is ever denied based upon ability to pay 	<ul style="list-style-type: none"> • Services vary by county • Aimed at people who have primarily mental health and/or substance abuse needs
<p>Emergency Room - Your local hospital's standard ER</p>	<ul style="list-style-type: none"> • Can discuss short and long term voluntary and involuntary commitment • No one is denied based on ability to pay • Available 24/7 in all areas 	<ul style="list-style-type: none"> • Focused on medical care instead of behavioral supports • Not preventative or focused on long-term options • May result in forced treatment situation

BIG TAKEAWAY
Crises are scary and you can't prepare for everything that could possibly happen. Instead, prepare for anything likely and have this contact sheet at the ready. Make sure other family members and caregivers know where to find it and that 911 shouldn't necessarily be the place you call for help in all emergencies.

Experiencing a Legal or Justice Crisis

If prevention, de-escalation, and working with a crisis team has not been successful, you may find your loved one with a developmental disability facing criminal charges. Or, perhaps, there was no crisis leading up to an arrest, but your loved one was picked up and arrested on suspicion of committing a crime. In either case, get there as soon as possible.

In Fairfax, you can request officers trained in Diversion First to work with you. In other counties, ask for officers with Crisis Intervention Training (CIT) backgrounds to work with your loved one. Remember that in all facets of the justice system, the Americans with Disabilities Act (ADA) applies (more information below). Your loved one should have *Miranda* rights read to them in a way they understood and that comprehension should be tested.

The National Alliance on Mental Illness's (NAMI) Northern Virginia Chapter has put out a fantastic guide on navigating the Fairfax County jail, called the Adult Detention Center. We highly recommend reading it here- http://www.nami-northernvirginia.org/uploads/2/4/4/0/24403592/navigating_the_fairfax_county_adult_detention_center_final_1st_edition.pdf.

Hiring an Attorney

If the person arrested is facing possible jail time, and they are in poverty (i.e. receiving Social Security benefits), they can be afforded a public defender. However, the public defender put on the case may have no experience with people with DD and you cannot change representatives for that reason. Your public defender is likely working on a number of cases and may have limited time to work with you. They are also not available if jail time is not being pursued as a putative option.

If you choose to hire an attorney, consider hiring an attorney with expertise in this field before speaking to officers. See Appendix VI for some attorneys who practice in this area of law. You can also contact a local bar organization for a recommendation. Attorneys can help you understand legal consequences and actions for what the person with a disability does and says. They are there to know the law and its complexities, and to support your loved one in understanding his or her rights and choices.

It is critical to understand that a privately hired attorney's time can cost hundreds of dollars per hour. Many families report spending tens of thousands of dollars in legal fees. You can always disclose your financial situation to potential attorneys and ask about reduced fees, payment plans, or other cost deferment options. However, at the end of the day, the costs of interactions with the justice system are almost always high.

Lastly, remember that the attorney's client is the person with a disability, even if you are paying for them. Have a designated point person with whom the attorney can communicate to make the lines of communication open and easy. Look into signing releases so the attorney can communicate with you as much as possible. No matter what, you can continue to provide helpful information (e.g., diagnoses) to the attorney.

BIG TAKEAWAY

If your loved one is ever arrested, it will be terrifying. Things will both move quickly and at other times seem to be at a standstill. Hire an attorney as soon as possible and communicate with them often.

After Arrest

The NAMI guide reference at the start of this section is a tremendous source of information on the process following an arrest. Some things likely to happen after someone is arrested are:

- Arrival at the jail, including interviews, screenings, and assessments
- Move to a general holding cell where the person can make a phone call (remember they should have the number memorized as their phone will be gone at this point)
- Intake completion which will result in their information showing up as an inmate, assignment of a court arraignment, and listing of charges filed against them
- Bail will be set by a magistrate or judge
 - You can pay bail or contact a bail bondsman
 - If bail isn't set, it will be set later in front of a judge at a hearing
 - You can refuse to post bail if there is no safe place for the person to go outside of jail or if you think they won't be able to comply with the terms of bail

Relevant Laws

- ❖ Title II of the **Americans with Disabilities Act (ADA)** of 1990 protects the rights of people with developmental disabilities in state and local government services. Anyone accessing the court system is entitled to reasonable accommodation as needed.

Examples include:

- Communication boards, software, or other devices
- Reader or facilitator to assist the person in explaining the process
- Interpreters
- Note takers
- Modified schedules
- Alternative seating locations

The ADA also applies to all interactions with police or law enforcement bodies. The police are required to make reasonable modifications to policies and procedures, such as modifying the way *Miranda* Rights are read or testing for understanding of *Miranda* by having the individual repeat the rights in his or her own words.

Once incarcerated, the ADA can require the provision of individualized instruction to understand rules and reward systems. Individuals with DD may have trouble with social interactions with other inmates and corrections officers and are more susceptible to

victimization. They may need help understanding how to use their commissary account and other seemingly simple procedures within the jail/prison.

- ❖ **HB1213** was enacted in 2016. The law permits certain educational records (e.g., IEPs, evaluations, behavior plans) to be admitted in court when juveniles with disabilities are charged with school-based misdemeanors. This is why you want everything possible included in the IEP or PLOP that relates to behavioral needs. The educational records will be able to show whether the behavior at hand was willful or intentional.

Working as a Team

Form a “defense team.” The team should include providers of community services as well as disability advocates who can attend court and assist in educating the judge and prosecution. It may also include seasoned attorneys in this field who can consult or lend ideas. This team can demonstrate that the defendant has a community willing to provide supports to prevent further incidents. Team members can serve as expert witnesses and develop a written alternative plan to incarceration. For example, they can put into place supervised, supportive living and working environments. They can set up counseling and other services the individual may need. The team should also include clinical experts who can speak to the nature and manifestation of the disability.

Examples of team members include psychologists, psychiatrists, Arcs or other advocacy organizations (including Formed Families Forward for fostered or adopted children and adults), Community Services Board staff, parents, trusted family and friends with knowledge of the accused, counselors, and attorneys who work in this field. Finding experts with a personal and professional connection is ideal.

BIG TAKEAWAY

Having a team to work with you will be key to any successes you have. Get people on board fast. Have everyone pitch in, lend ideas, and share their talents. Everyone has something they can do—file the loads of incoming paperwork, offer to visit someone who is arrested, research support options, etc.

Personalized Justice Plans

The work of The Arc of New Jersey on Criminal Justice Advocacy is the basis for the parallel version of this guide, A Guide for Attorneys. Their program was established in 1985 and is rich with resources. The site features personalized justice plan options to facilitate jail diversion and archived webinars for attorneys on representing clients with developmental disabilities. These plans show everyone involved in the court process how the need for treatment, justice, and other legal needs can be met while meeting the needs of the person with a developmental disability.

Their document on a Personalized Justice Plan is below. It can be found online at http://www.arcnj.org/programs/criminal_justice_advocacy.html

PUT IT IN WRITING ! : The Importance of a Personalized Justice Plan (PJP) in Providing Successful Assistance to People with I/DD in the Criminal Justice System

The Criminal Justice Advocacy Program has been a part of The Arc of NJ since 1985. Since its inception, the primary goal has been to provide an alternative to incarceration for people with I/DD. To accomplish that goal, the creation of a Personalized Justice Plan (PJP) for individual clients is the best opportunity to educate and inform the Court and counsel about needed services and support that can be provided to that individual. When accepted by the Court, a PJP is a mechanism for addressing the individual's needs while requiring the accountability for criminal actions that the criminal justice system seeks.

First, in the introduction of a PJP, we can take the opportunity to introduce counsel and the Courts to developmental and intellectual disabilities, tailoring the PJP to describe this individual's disability and how that cognitive impairment may impact on their involvement in the criminal justice system.

For example:

This individual has an established and documented developmental disability, having been found eligible for services from the Division of Developmental Disabilities. The most recent neuropsychological evaluation indicates that Mr. has "symptoms ... consistent with those demonstrated by individuals with alcohol-related neurodevelopmental disorders, including Fetal Alcohol Effects and Fetal Alcohol Syndrome."

Fetal Alcohol Spectrum Disorders (FASD) is a cluster of permanent, non-curable brain disorders and physical malformations, caused by women drinking alcohol during pregnancy. Primary disabilities caused by FASD include hyperactivity, poor judgment, attention deficits, extreme impulsivity, learning disabilities, short memory spans, perceptual disorders, anxiety, lack of social skills, difficulty with abstract thinking and difficulty retrieving information. As a result, persons with FASD show secondary disabilities such as being easily victimized, failing to learn from prior experience, failing to understand consequences of actions, showing poor frustration tolerance, having poor personal boundaries, having difficulty handling money and are easily distracted and led

by others. Some but not all persons diagnosed with FASD also have an intellectual disability; 25% will have IQ scores of 70 or below. Nonetheless, a person with FASD will often have learning disabilities which interfere with sound judgment and can cause behavioral problems that significantly impact his or her life. Fetal Alcohol Syndrome (FAS), by Sharon Davis and Leigh Ann Davis, The Arc of the United States, April 2003. For example, here, neurological testing demonstrated a full scale IQ of 79 but with many deficits of functionality related to organization, impulsivity and abstract thinking. It is, however, important in this case to note that once FAS has been diagnosed, secondary disabilities can be reduced and in some circumstances prevented. Interventions need to be consistent and constant and would need to include supervised home care and supervised employment.

Or for example:

He has an established and documented developmental disability, having been found eligible for services from the Division of Developmental Disabilities. Mr. 's neurological testing demonstrated a full scale IQ of 54 but with many deficits of functionality related to organization, impulsivity and abstract thinking. His most recent neuropsychological evaluation indicates that he has Tourette's Disorder which is associated with vocal and motor tics, hyperactivity, anxiety and compulsive behavior. According to school records, he has a history of impulsivity, learning problems and poor interpersonal boundaries.

The National Tourette Syndrome Association makes clear that Tourette Syndrome and other tic disorders occur in all ethnic groups. Males are affected 3 to 4 times more often than females. Most people with Tourette Syndrome and other tic disorders will lead productive lives. A person with Tourette Syndrome can be found in all professions. Yet the co-occurring behaviors or disorders such as learning, attention deficit hyperactivity, compulsion in addition to tics may cause significant impairment in social, occupational or other important areas of functioning

Next, a PJP addresses multiple areas, including housing, therapy, jobs, activities in the community, social skills, in other words, every area of a person's life that can impact on their ability to live offense-free in the community. The first step is to obtain as much information about the individual as possible, including psychological evaluations, medical information, family contacts and ties in the community, work history, criminal history and any other piece of information that can help identify needs. (A release of information, signed by the individual or guardian, is required).

The next step is identifying existing services that the individual may be eligible for, including disability service providers such as residential providers, supported employment and recreational activities ; and therapeutic services such as sex offender specific treatment, drug or alcohol abuse treatment, social skills training, sex education ; and any other services that can be effective in keeping an individual on a path to being a productive member of the community.

A PJP can ultimately be finalized and condensed into a letter which can be broken down into areas to be addressed such as the one below:

Residence: Currently, Mr. resides by himself, with daily supervision and support from his parents. They have been, since this incident, providing and will continue to provide increased levels of supervision, and monitoring his behavior when in the community. They will also support Mr. in making choices so he will not enter into situations that may be more difficult than he can navigate.

Vocational Training\Employment: Mr. has been referred to the Division of Vocational Rehabilitation Services (DVRS), the state agency that provides vocational training and job placement to individuals with disabilities. For now, Mr. 's case is on hold until his legal matter has been addressed, as it has had a significant negative impact on his ability to find work. He was offered work with Acme Supermarket but the offer was rescinded upon discovery of these pending charges.

Counseling: Currently, Mr. is receiving a weekly counseling session from Dr. , Psy.D. Dr. has been working with Mr. for several years now, and will be continuing to provide therapy in the forms of role playing, sex education, socialization, and appropriate social interactions. Dr. is creating a safety plan for Mr. and his family to use as a tool to assist in making wiser choices.

Advocacy: is Mr.'s current DDD case manager, which means that she identifies community services, relays that information to the family for follow-up, and provides case management services in the community. Additionally, one of the coordinators from this program will remain in contact with Mr. and the other parties involved. We will ensure that Mr. is receiving appropriate services, as well as assist and encourage him in meeting any conditions set forth by the court.

Stipulations: These include any stipulations ordered by the court or the probation department. We will work with the probation officer and monitor the plan for the duration of the term and provide updated progress reports as requested. Also, Mr. must be willing to cooperate with the CJAP by following the PJP to the best of his ability.

While the PJP ordinarily follows this format, the actual supports and services included vary widely, since they are tailored specifically to the needs and circumstances of the individual. No two PJPs will look the same.

In contrast to the PJP language above, this client has a different set of needs:

Residence: Mr. resides in an apartment just a few hundred yards from his parents' home. They are very active and involved in his life and provide supervision to him in the evenings. Now the father of a newborn daughter, Mr. is committed to providing a stable and safe home life for her as well.

Vocational Training\Employment: Mr. is eligible for The Division of Vocational Rehabilitation Services (DVRS) and will begin vocational counseling there at earliest possibility. Mr. 's learning and functional ability will be assessed, as well as his vocational strengths, in order to best support him in procuring and engaging in full-time

employment. He would use public transportation or be driven by a family member to access DVRS' services.

Counseling: Mr. has begun seeing Dr., PsyD for regular therapy sessions. He has also been attending weekly Alcoholics Anonymous meetings, and will be increasing his attendance to twice weekly. He accessed these sessions and meetings via public transportation or is driven there and back by a family member. CJAP and DDD will continue monitoring and ensuring he receives the type and frequency of counseling services needed.

Advocacy: is Mr. 's current DDD case manager, which means that she identifies community services, relays that information to the family for follow-up, and provides case management services in the community. Additionally, CJAP will remain in contact with Mr. and the other parties involved. We will ensure that Mr. is receiving appropriate services, as well as assist and encourage him in meeting any conditions set forth the court.

Stipulations: These include any stipulations ordered by the court. We will monitor the plan for the duration of the term and provide updated progress reports as requested. Also, Mr. must be willing to cooperate with the CJAP by following the PJP to the best of his ability.

Finally, the individual must be willing to cooperate with the recommendations in the PJP and be compliant with conditions placed on them by the Court. A case file is held open until completion of a probationary sentence, while charges are held in abeyance or while the individual completes a pre-trial program such as Drug Court, and a community care coordinator from our program coordinates services and keeps the Court or parole informed of progress.

Reducing recidivism along with successful integration into the community are the ultimate goals of this process. Organizing the information and creating a PJP makes it easier for criminal justice system professionals to understand and access the social service system, and ensures that the defendant and all involved parties understand the conditions and can work to meet them.

BIG TAKEAWAY

A personalized justice plan is a proactive way to show a judge and prosecutor that there are good, fair alternatives to incarceration.

Preparing for Court

If you ultimately do go to court, spend time role playing and explaining what it may be like. Let them know they can talk to their attorney in a whisper or have their attorney clarify what is going on at the time. Other pointers are below.

- Ensure the person understands what appropriate court dress and behavior are. Give examples. Include grooming needs.
- Help them learn that court will not look like what they may have seen on television.
- Let them know when they will be allowed to speak (if ever) and how they are allowed to react and manage emotions.
- Tell them what to do if they are overwhelmed or do not understand what is happening. Have them practice this response with their attorney.
- Let them know when you will be mentioning their disability and other personal information that may make them feel vulnerable or self-conscious.
- Think long and hard about having them testify if they are someone who can easily be persuaded or confused by others as cross examinations or questioning by others may go awry.

Helping to Inform the Defense

The defense will have to weigh possible strategies for defense against the consequences. Be available and prepared to help them find evaluations and diagnoses from the past and possibly pursue new evaluations. See Appendix IX for ideas on obtaining updated evaluations. Here are some questions the attorney will have to consider.

- Did the person understand right vs. wrong?
- Did they understand what they were doing is a crime?
- Were they able to formulate intent?
- Was an irresistible impulse (subset of insanity defense) in play?
- Are they competent to confess, stand trial, or plead guilty?

To be found competent to stand trial, defendants must have both a rational and factual understanding of the nature of the proceedings against them, and be able to effectively assist counsel in preparing their defense. An evaluation based on IQ and adaptive functioning is critical.

Note: It can be dangerous to pursue a defense focused on incompetency. If someone is deemed incompetent, they may be locked in a mental health or other treatment facility without an opportunity to show that their actions were the direct result of their disability and, with supports, the actions can be prevented from reoccurring.

- Did/can the person understand *Miranda* rights?
The *Miranda* rights are generally found to be at a 7th grade level while someone with an intellectual disability with an IQ around 70 may read at a sixth grade level or below.⁶
- Your attorney may consider writing a letter to the prosecution and the judge outlining the disability and its clear manifestation in any alleged criminal action. This will allow an opportunity for this to be reviewed ahead of any hearings or sentencing. One family we recently worked with cited this as being one of the keys to success. Her son’s attorney presented a great deal of research, professional evaluations, and his own evaluation of the client directly to the prosecutor outside of court.

BIG TAKEAWAY

You have limited opportunities in front of the judge and with attorneys. Research, work with your team, and be ready to share evidence and raise questions in quick windows of time. Don’t assume any rights will be in place for you as a parent or loved one. Plan to find ways to make your voice or message heard through diagnoses, letters, and justice plans.

Consequences of Conviction

While a criminal conviction makes life more difficult for anyone, people with developmental disabilities are particularly vulnerable. This population usually relies on at least some form of public support services if their disability prevents them from working, living, or socializing independently. These programs can be jeopardized permanently, thereby leaving the person with no options at all for a successful independent life.

- Criminal convictions almost always result in a red flag or barrier to any sort of **affordable housing** opportunity. A huge number of people with developmental disabilities rely solely on Social Security benefits or benefits combined with a small salary and it is impossible to live on that money without affordable housing supports. Some crimes can be reconsidered under an accommodations process if the crime is the direct result of the disability AND disability-related supports are in place to prevent reoccurrence. However, sexual crimes, including Megan’s Law registration for life, bars someone from accessing housing supports through the federal Housing and Urban Development agency permanently.
- For individuals receiving **Social Security benefits**, those benefits will be suspended if the person becomes incarcerated. Imprisonment lasting over one year requires a new application for Social Security benefits, a process that can take many months or over a

⁶ http://www.thearc.org/file/documents_initiatives_nccjd/NCCJDTipSheet_Attorney_CopyrightBJA.pdf

year. That could mean the person leaves with no income and will not have any income (unless they're able to find work and obtain supports needed to maintain the job) for months after a release from jail.

- **Medicaid health insurance** is contingent upon receipt of Social Security benefits for adults with disabilities. This can mean not only no health insurance, but no funding for the core support services for people with developmental disabilities in Virginia called "**Medicaid Waivers.**" (see Appendix XII for more information)
- Many criminal convictions, even for minor offenses, can be barrier crimes to working with children, animals, or the aging population. These are **job fields** of common interest for people with disabilities.

BIG TAKEAWAY

Convictions for even minor offenses can have long-term consequences. Focus on avoiding any permanent issues (e.g., lifetime listing on the sex offender registry) and notifying any public benefits of the outcome of the case right away.

Legal Authority, Guardianship, and the Dignity of Risk

We are often asked about the need for and value of guardianship and other forms of legal authority, especially as they relate to “protecting the person.” The answer to what is appropriate depends upon the person. *It is critical to remember that guardianship and similar measures are simply legal authority on a piece of paper. They cannot prevent someone from doing something or undo something that has been done. Guardianship does not necessarily mitigate the view of judges, prosecutors, or police officers.* Having guardianship may or may not be taken into account in justice situation and it is not used to determine competency.

We talk more and more about the “dignity of risk” and its value. The concept is simply that all people need help making some decisions and we all learn by making bad decisions. For example, many people without developmental disabilities rely on tax accountants or doctors to explain life decisions in simple terms they can understand. This idea is called [“supported decision making”](#) and there is a growing international movement towards this policy. This is included in the international Convention on the Rights of Persons with Disabilities, though the U.S. has yet to ratify that law. Simply put, a team of people who care about the person with a disability are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights but does build a support team and a way to grow decision making ability and independence over time.

“Dignity of Risk” also means understanding that it is okay to make some bad decisions. We are all allowed to do this, and it is often how we learn best. For example, many people learn from hangovers not to drink too much, learn from spending too much that it is hard to pay bills, and learn from weight gain and health issues that they ate too much. This is a right all people have and exercise every day. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed the next time.

If you do explore guardianship or other legal authority, remember that no matter what you legally sign and agree to do, the person with a disability ultimately consents by participating or not.

Guardianship and Conservatorship

Guardianship or conservatorship is a legal, court-ordered relationship in which one individual is appointed by the court to become the substitute decision maker for another. The substitute decision making by a guardian and/or conservator is the most restrictive form of limiting legal rights, restricting **all** legal decisions that arise in the life of the incapacitated person.

Alternatives to Full Guardianship

Limited Guardian of the Person: The courts can limit or specify the authority and responsibilities of the guardian to specific areas of the individual’s life; such as medical and health care decisions. The courts can maintain specific rights for an individual through a written order, for example, the rights involving voting, marriage, and driving.

Medical Power of Attorney: An agreement that grants an individual the authority to act on someone else's behalf for health-related matters. This allows the individual to make decisions about things like medical treatments, prescriptions, and nursing home arrangements.

Durable Power of Attorney: A durable power of attorney will remain in effect for the person designated as an individual with the authority to act on someone's behalf even if the individual later becomes mentally incapacitated.

General Power of Attorney: The general power of attorney gives the agent broad power to do almost anything for you, the principal. However, if the principal is later deemed incapacitated, the General Power of Attorney is no longer valid.

Special Education Power of Attorney: This document allows an appointed decision maker to participate in/consent to IEPs and other school documents. It is only valid in public primary and secondary schools, not universities/colleges. You can find a template here:
http://www.doe.virginia.gov/special_ed/regulations/state/transfer_rights_students_disabilities.pdf

Representative Payee: A person appointed by the Social Security Administration to manage an individual's governmental benefits to pay living expenses and daily needs.

Temporary Guardianship: For specific reasons, a person can be appointed as temporary guardian on a time-limited basis. For example: to assist in moving an individual to a residential placement; to make medical decisions, etc.

Alternatives to Conservatorship

Limited Conservatorship: The courts can limit the authority of the conservator to specific areas of the individual's life. For example, the sale of a property, establishing a trust, or handling estate matters. Limited conservatorship can also be time-limited.

Special Needs Trust: An arrangement with a trustee (another person, an attorney, an organization or a financial institution) to manage property or assets for the benefit of an individual.

Financial Power of Attorney: An individual appoints a person to serve as their agent to make decisions on their behalf.

Representative Payee: A person appointed by the Social Security Administration to manage an individual's governmental benefits to pay living expenses and daily needs.

Temporary Conservatorship: For specific reasons, a person can be appointed as a temporary conservator on a time-limited basis. For example: to assist in moving the individual's assets to another agent; to manage assets of an estate; make financial decisions regarding buying or selling property such as a home or car; to handle inheritance, etc.

Obtaining Legal Authority

Guardianship and conservatorship (full, limited, and temporary) all involve court processes. Generally, the person seeking guardianship hires an attorney who meets with the individual and individual who may be in need of decision making supports. The attorney will ask for

evaluations showing a diminished ability to make decisions and relevant diagnoses. Then the attorney will work with the courts to have a Guardian ad Litem (GAL) appointed. The GAL is an independent attorney who should meet with the individual and proposed guardian to ensure the proposed arrangement is appropriate and ensure the individual understands what is going on, to the best of his or her ability. If all goes well, the parties appear briefly before a judge in civil court for a legal appointment to take place. It is very important to work with an attorney experienced in this field. The process usually takes a handful of months and costs about \$3,000-\$4,000. For a list of attorneys in this field see Appendix VIII.

[Powers of Attorney](#) can be drafted by attorneys or you can use an online template. They are notarized, which can often be done by your local bank or any other notary. The cost is minimal or free (if you find a free template, customize it, and have a free notary).

[Representative Payees](#) are put in place by the Social Security Administration. There is no legal process to do this. It is quick and free.

[Special Needs Trusts](#) are set up with a non-profit (such as [The Arc of Northern Virginia](#)), an attorney, or a bank. There is usually a fee to establish the trust. The fee is \$1,050 at The Arc of Northern Virginia. There is then a fee to manage the trust, usually a small percentage of the value of the trust.

BIG TAKEAWAY

Guardianship does not protect a person or give parents extra rights during criminal cases. Think carefully about restricting rights and focus on growing decision making ability and supports that are strong tools for preventing criminal acts.

Core Support Services

One of the keys is building a support network around the person with a disability that can help demonstrate a decreased likelihood of future criminal activity and that will be adding in routine support services for daily living, jobs, housing, etc. The Arc of Northern Virginia provides a great deal of free information and referral for families needing these resources. Families can reach out anytime at 703-208-1119 or info@thearcofnova.org.

These are some of the most frequently used support services available to people with developmental disabilities.

- 1. Waivers** - A Waiver is a long-term support system for someone who will have long-term care needs, including someone with a developmental disability. Once a person is awarded a Waiver, they will have access to a menu of services offered by their Waiver. Frequently used services include attendants who work one on one with the person with a disability, respite care so parents can have a break from care provision, group home supports where a person with a disability lives in a home shared by other people with disabilities, long term employment or meaningful day services, assistive technology, environmental modifications, nursing, and more. These services are offered at no or very low cost.
Waivers do have a waiting list, but involvement with the justice system can significantly accelerate the process. Ask your client if they are already on a waiting list for a Medicaid Waiver. If so, have them contact their local Community Services Board (see Appendix III) to update their status for the waiting list. If they are not already on the waiting list, they can apply now by contacting their local Community Services Board.
- 2. Private caregivers** - Someone without a Waiver can hire a private caregiver to support the person with a disability in a variety of ways. This person can help with the development of social skills, day to day living needs, or on practicing behavior and emergency management. Care.com, sittercity.com, and craigslist.org are common, large forums for searching for these caregivers. The Arc of Northern Virginia developed and maintains a guide to help families in navigating this process both with and without a Waiver. To request a copy, please email lucy.beadnell@thearcofnova.org.
- 3. Department of Aging and Rehabilitative Services (DARS)** - DARS is Virginia's free job coaching agency. Job coaches assist people with disabilities in job readiness (e.g., resume writing, interview preparation), job location, securing a job, and maintaining a job. Their services are limited in terms of time and scope, but they are free and sometimes have a short waiting list or no waiting list at all for our population. Getting a job increases self-esteem and increases income which can be two giant leaps towards helping someone with a developmental disability move towards successful, safe community living.
- 4. Private Job coaching** - Just as families can hire private caregivers when a Waiver is not available, they can also hire private job coaches if DARS services have a waiting list or are not the best possible fit. Job coaches hired privately can work as much or as little with a client as needed and can help problem solve around a possible criminal history or other work barriers. See Appendix XIII for options.

5. **Housing** - It is hard to imagine someone successfully moving on in life without a safe place to live. Depending upon age, need, and preference, some people with developmental disabilities will choose to continue living at home with family. Many adults, though, will need a plan for housing, as well as services. A 2012 Department of Justice settlement with Virginia has pushed Virginia towards more integrated housing options, so more options are becoming available. Housing alone is often not enough, so it is important to also consider services (see Waivers and private caregivers above) to explore those options.

Types of housing include the following. For a more comprehensive list, see The Arc of Northern Virginia's Transition POINTS: Housing Guide at

<https://thearcofnova.org/programs/transition/finding-home-adults-disabilities/>

- Person with a disability uses a Waiver for Supported Living where their home is owned by a service provider who comes in a certain number of hours per day.
- Person uses a Disability Waiver for Independent Living where supports are brought into a home the person acquires using a housing voucher or other affordable program (or family owned home).
- Person with a disability rents a two person apartment and the room, board, utilities, etc. for the roommate without a disability are covered by the Waiver in exchange for supports. This is called Shared Living.
- Sponsored Residential housing where the person with a disability lives in the home of a paid caregiver.
- Group Home where 24/7 staff are available to a group of 3+ people with developmental disabilities who share a living space and support staff.
- Housing Voucher Program that allows the person to rent an affordable apartment with just 30% of their income. They must find separate means to bring in staff, including using the Waiver.
- Individual lives in public housing or a tax credit property that has a reduced rent unit in place where a person can bring in their own support services.

Transition POINTS Guides - The Arc of Northern Virginia has free resource guides that cover early intervention and young children, special education in the school setting, futures planning, housing, jobs, and aging. They are great resources to peruse for tossing out a wide net on resource navigation. Available at <https://thearcofnova.org/programs/transition/>

BIG TAKEAWAY

There are lots of options to pursue for support services and housing. Public options usually have waiting lists and private options are usually expensive. However, preventing jail time is invaluable. Have your support team help you explore support options.

Advocacy

Laws are created and changed because people ask for them and fight for them. The Arc of Northern Virginia devotes a great deal of time and energy to advocating for changes that will better serve the developmental disability population and our community at large.

Most of the laws that will affect the way your loved one is routed through the justice system are state laws. Though federal laws (such as the IDEA and the ADA) set guidelines on our educational and public systems, they rarely get deep into the details of how all protections will be implemented. It is left to states to determine what specific issues they feel are a priority and to either draft legislation or provide funding to support those priorities.

State Advocacy

We invite you to join us in the effort to reform our justice system to be better for everyone. You can reach us anytime at www.thearcofnova.org or 703-208-1119. We also encourage you to contact your General Assembly member to share your thoughts on the needs for funds for police and emergency services training, laws that better accommodate disability, and other justice-related needs.

Find your state representative here (<http://virginiageneralassembly.gov/>) by clicking the “Who’s My Legislator” box at the top of the page and typing in your address. You will have one state Senator and one Delegate. You may contact them both to share thoughts, ask for a conversation, to set up a meeting, or propose a bill. You can go to their websites and sign up for their email alerts to find out when they will have Town Hall meetings or other open forums for you to share your thoughts and concerns.

Local Advocacy

Though legislative changes and most funding comes through the state, don’t forget about your local representatives in county or city government. They will help steer and set priorities for programs like Diversion First.

In all cases, vote! Tell your legislators why you voted. Ask questions about disability and justice issues during the campaign, especially people campaigning for positions as Sheriff or Commonwealth’s Attorney. They will set the lead on which cases are prosecuted and how disability justice issues are faced as whole.

BIG TAKEAWAY
You have the power to change laws and processes that are unjust. It will be hard, but without hearing from you, legislators don’t even know there is a problem.

Appendices

Appendix I: National Center on Criminal Justice and Disability (NCCJD)

The NCCJD is a program of The Arc's national office. It is an effort to bring together issues of victimization of people with DD as well as suspect and offender issues. The center is a "national clearinghouse" on these topics. The center hosts and creates materials on justice issues related to the DD community. The program's website is <http://www.thearc.org/NCCJD>

Online programming includes:

- Archived webinars from attorneys and other professionals on topics including competency, autism and sex crimes, and models of justice reform programs from around the country - <http://www.thearc.org/NCCJD/training/webinars/archive>
- Perske's list, overviewing cases of coerced false confessions from people with DD - <http://www.thearc.org/NCCJD/materials/perske-list>
- An attorney fact sheet - http://www.thearc.org/file/documents_initiatives_nccjd/NCCJDTipSheet_Attorney_CopyrightBJA.pdf
- A Justice Advocacy Guide - <http://www.thearc.org/document.doc?id=3669>
- Training materials for justices and others in the court system - <http://www.thearc.org/NCCJD/training>
- State-based resource directory - <http://www.thearc.org/NCCJD/resources/by-state>
- A forum to request assistance from The Arc - <http://www.thearc.org/NCCJD/about/request-assistance>
- A 2006 guide on victimization and what to do if arrested - <http://www.thearc.org/document.doc?id=3669>

Appendix II: Arc Chapters in Virginia

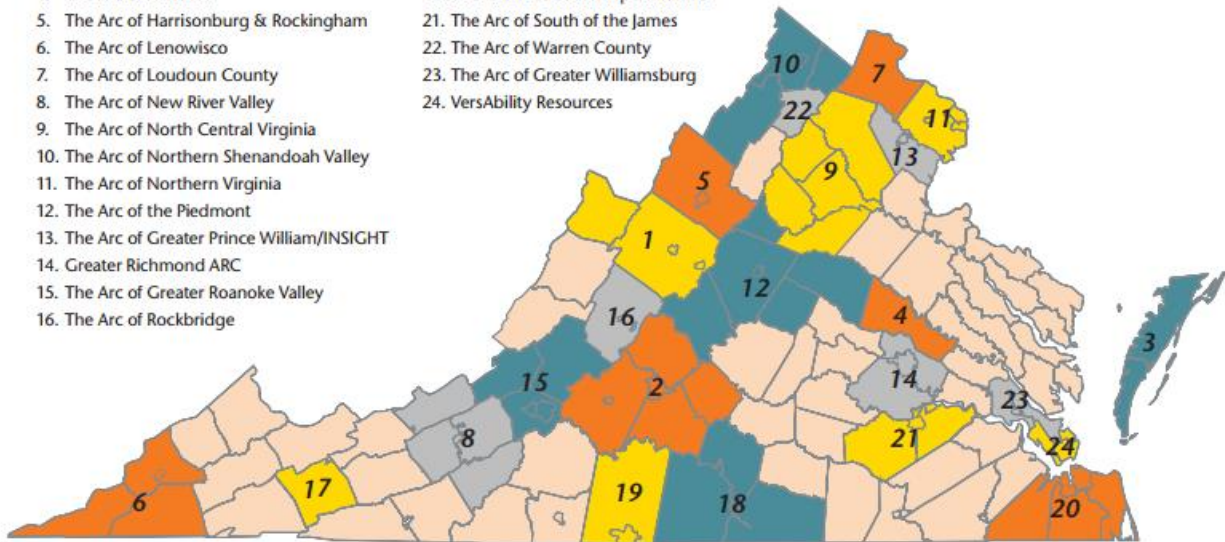
Virginia has 24 chapters of The Arc, all specializing in different geographic regions and topics. This guide was produced by The Arc of Northern Virginia and Paxton Campus, The Arc of Loudoun (with consent from The Arc of New Jersey). You can view the following map of chapters created by The Arc of Virginia here- <http://www.thearcofva.org/wp-content/uploads/2015/09/Local-chap-map.pdf>.



Local Chapters of The Arc of Virginia

 The Arc of Virginia serves the entire Commonwealth.

- | | |
|---|-------------------------------------|
| 1. The Arc of Augusta | 17. The Arc of Smyth County |
| 2. The Arc of Central Virginia | 18. The Arc of Southern Virginia |
| 3. The Arc of Eastern Shore | 19. The Arc Southside |
| 4. The Arc of Hanover | 20. The Arc of South Hampton Roads |
| 5. The Arc of Harrisonburg & Rockingham | 21. The Arc of South of the James |
| 6. The Arc of Lenowisco | 22. The Arc of Warren County |
| 7. The Arc of Loudoun County | 23. The Arc of Greater Williamsburg |
| 8. The Arc of New River Valley | 24. VersAbility Resources |
| 9. The Arc of North Central Virginia | |
| 10. The Arc of Northern Shenandoah Valley | |
| 11. The Arc of Northern Virginia | |
| 12. The Arc of the Piedmont | |
| 13. The Arc of Greater Prince William/INSIGHT | |
| 14. Greater Richmond ARC | |
| 15. The Arc of Greater Roanoke Valley | |
| 16. The Arc of Rockbridge | |



Contact information for the Virginia chapters of The Arc is below. Visit <http://www.thearcofva.org/about-the-arc/local-chapters/> for updates.

The Arc of Northern Virginia

Rikki S. Epstein, Executive Director

2755 Hartland Road, Suite 200, Falls Church, VA
22043

P: (703) 208-1119 F: (703) 208-0906

repstein@thearcofnova.org

www.thearcofnova.org

Paxton Campus, The Arc of Loudoun County

Jennifer Lassiter, Executive Director

601 Catoctin Circle, NE, Leesburg, VA 20176

P: (703) 777-1939 F: (703) 779-2708

jlassiter@paxtoncampus.org | www.paxtoncampus.org

The Arc of Augusta

Warren McKeen, Executive Director

1025 Fairfax Avenue, Waynesboro, VA 22980

P: (540) 943-1618 F: (540) 943-1618

arc102@ntelos.net | www.thearcofaugusta.org

The Arc of Central Virginia

Karen Wilder, Executive Director

1508 Bedford Avenue, Lynchburg, VA 24504

P: (434) 845-4071 F: (434) 845-6425

info@arcofcva.org | www.arcofcva.org

The Arc of Eastern Shore

Suzanne Joyner, Office Manager

P.O. Box 626, Exmore, VA 23350

P: (757) 442-3312 F: (757) 442-3602

arc.esva@verizon.net

The Arc of Hanover

Caroline Kistler, Executive Director

P.O. Box 91, Ashland, VA 23005

P: (804) 798-2400 F: (804) 798-0310

info@hanoverarc.org

www.theArcofHanover.org

The Arc of Harrisonburg & Rockingham

Heather Denman, Executive Director

620 Simms Avenue, Harrisonburg, VA 22802

P: (540) 437-9214 F: (540) 437-9217

execdir@hrarc.org | www.hrarc.org

The Arc of Lenowisco

Julia F. Lewis, President

2532 4th Avenue East, Big Stone Gap, VA 24219

P: (276) 431-4159

jflewis@frontierhealth.org

The Arc of New River Valley

Mac McArthur-Fox, President

P.O. Box 11204, Blacksburg, VA 24062-1204

P: (540) 558-9510

communityopportunities@yahoo.com

The Arc of North Central Virginia

Marilyn McCombe, President

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arcofnorthcentralva@gmail.com

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The Arc of Northern Shenandoah Valley

Niki Pangle, Executive Director

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22663

P: (540) 445-1272 F: (540) 665-2806

arcnsv@verizon.net | www.thearcofnsv.net

The Arc of the Piedmont

John Santoski, Executive Director

509 Park Street, Charlottesville, VA 22902

P: (434) 977-4002 F: (434) 984-0577

jstantoski@thearcofthepiedmont.org | www.t

hearcofthepiedmont.org

The Arc of Greater Prince William/INSIGHT

Karen Smith, Executive Director

13505 Hillendale Drive, Woodbridge, VA 22193

P: (703) 670-4800 F: (703) 670-8648

ksmith@arcgpw.org | www.arcgpw.org

Greater Richmond ARC

John Walker, President

3600 Saunders Avenue, Richmond, VA 23227

P: (804) 358-1874 F: (804) 353-0163

john.walker@richmondarc.org

www.richmondarc.org

The Arc of Greater Roanoke Valley

Cole Keister, President

P.O. Box 13382, Roanoke, VA 24033-3382

P: (540) 520-1880

arcgrv@yahoo.com | www.arcgrv.org

The Arc of Rockbridge

Robin Richarde, Executive Director

P.O. Box 657, Lexington, VA 24450

P: (540) 460-2710 F: (540) 348-5510 *call first

thearcofrockbridge@yahoo.com

The Arc of Smyth County

Jo Bangle, Office Administrator

P.O. Box 1495, Marion, VA 24354

P: (276) 783-6801

arc-smythcounty@smyth.net

The Arc South of the James

Shareen Young-Chavez, President

P.O. Box 272, Colonial Heights, VA 23834

P: (804) 446-1705

thearcsoj@gmail.com | www.thearcsoj.org

The Arc of Southeastern Virginia

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info@thearcofseva.org | www.thearcofseva.org

The Arc of Southside

Tonya Fowler, Executive Director

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director@thearcofsouthside.org

www.thearcofsouthside.org

The Arc of Southern Virginia

Elsie Gladding, President

P.O. Box 252, Halifax, VA 24558

P: (434) 222-8931

thearcofsova@gmail.com

The Arc of Warren County

Michael Hirsch, President

P.O. Box 1473, Front Royal, VA 22630

P: (540) 635-2725 ext. 33242

mhirsch@wcps.k12.va.us

The Arc of Greater Williamsburg

Pam McGregor, Executive Director

150 Strawberry Plains Rd., Suite D,

Williamsburg, VA 23188

P: (757) 229-3535

pam.mcgregor@thearcgw.org | www.thearcgw.org

VersAbility Resources

Kasia Grzelkowski, President and CEO

2520 58th Street, Hampton, VA 23661

P: (757) 896-6461 F: (757) 896-8470

kasia@versability.org | www.versability.org

Appendix III: Community Services Boards and the Department of Behavioral Health and Developmental Services

Community Service Boards (CSBs) are the single point of entry for people with developmental disabilities seeking public supports in the form of Medicaid Waivers, case management, and many other services. A list of Northern Virginia area CSBs is below. You can find another CSB through this link

<http://www.vacsb.org/directory.html>

Alexandria CSB

720 N. Saint Asaph Street

Alexandria, VA 22314

Phone: 703-746-3400

Emergency: 703-746-3401

Coverage Area: Alexandria City

<http://www.alexandriava.gov/mhmrca>

Coverage Area: Aldie, Ashburn, Bluemont, Chantilly, Dulles, Hamilton, Hillsboro, Lansdowne, Leesburg, Lincoln, Loudoun, Lovettsville, Middleburg, Neersville, Paeonian Springs, Philimott, Purcellville, Round Hill, South Riding, Sterling, Waterford, The Plains

<http://www.loudoun.gov/index.aspx?NID=121>

Arlington CSB

1725 N. George Mason Drive

Arlington, VA 22205

Phone: (703) 228-5150

Emergency: (703) 228-5160

Coverage Area: Arlington County

<http://www.arlingtonva.us/csb>

Prince William CSB

8033 Ashton Avenue, Suite 107

Manassas, VA 20109

Phone: (703) 792-7800

Emergency: (703) 792-7800

Coverage Area: Manassas, Manassas Park, Bristow, Dale City, Dumfries, Gainesville, Haymarket, Montclair, Nokesville, Occoquan, Prince William, Quantico, Triangle, Woodbridge

<http://www.pwcgov.org/default.aspx?topic=040054>

Fairfax-Falls Church CSB

12011 Government Center Parkway, Suite 836

Fairfax, VA 22035

Phone: (703) 324-7000

Emergency: (703) 573-5679

Coverage Area: Annandale, Burke, Centreville, Clifton, Fairfax City, Fairfax County, Fairfax Station, Falls Church, Great Falls, Herndon, Springfield, Vienna

<http://www.fairfaxcounty.gov/csb>

Rappahannock Area CSB

600 Jackson Street,

Fredericksburg, VA 22401

Phone: (540) 373-3223

Emergency: (540) 373-6876

Coverage Area: Bowling Green, Carmel Church, Caroline County, Ladysmith, Milford, Port Royal, Rappahannock Academy, Ruther Glen, Woodford, Fredericksburg, Dahlgren, King George, Lake Anna, Spotsylvania, Thornburg, Falmouth, Stafford

<http://www.racsb.state.va.us>

Loudoun CSB

906 Trailview Blvd,

Leesburg, VA 20175

Phone: (703) 777-0378

Emergency: (703) 777-0320

The Department of Behavioral Health and Developmental Services (DBHDS) is the state agency tasked with governing the Community Services Boards, administering the Waivers, and overseeing state developmental services. <http://dbhds.virginia.gov/individuals-and-families/developmental-disabilities>

Key contacts at DBHDS include:

1. Heather Norton, Director, Community Supports Services, Heather.Norton@dbhds.virginia.gov, (804) 786.5850
 - a. Contact for concerns about community supports and needed supports to promote diversion
2. Jennifer Kurtz, Northern Virginia Community Resource Consultant, Jennifer.kurtz@dbhds.virginia.gov, (804) 461-0256
 - a. Contact for problem solving and barrier busting in Northern Virginia related to state services
3. Tim Simmons, Northern Virginia Human Rights Representative, Tim.Simmons@dbhds.virginia.gov, (703) 207-7217
 - a. Contact for concerns of the violation of human rights of people with developmental disabilities in service settings
4. Jeannie Cummins, Northern Virginia Senior Integrated Community Options Specialist, j.cummins@dbhds.virginia.gov, (804) 836-4308
 - a. Contact for housing concerns and needs to prevent incarceration or plan for release

Appendix IV: Department of Justice Contacts

The guide briefly mentions a settlement agreement between the **Department of Justice** and Virginia from 2012, running for at least ten years. The agreement is designed to improve the availability of community based, integrated services for people with developmental disabilities.

Attorneys on the case:

Kyle Smiddie
202-532-3249

Smiddie.Kyle@usdoj.gov

Jessica Polansky
202-353-1280

Jessica.Polansky@usdoj.gov

Northern Virginia also has a Department of Justice attorney based in Alexandria specializing in ADA violations. Steven has worked closely with local police departments on **ADA issues**.

Steven Gordon
703-299-3817

steve.gordon@usdoj.gov

Appendix V: Statewide Legal, Advocacy, and Protective Organizations

The disAbility Law Center is Virginia’s public protection and advocacy organization. Their work focuses on advancing human and civil rights, legal rights, human and civil rights for people with disabilities and ending discrimination through legal representation and advocacy.

800-552-3962, <http://www.dlc.v.org/>

Adult Protective Services is the state agency tasked with ensuring adults with disabilities are not abused, neglected, or exploited. You can reach them 24/7 to report suspected abuse, neglect, or exploitation and have it investigated.

888-832-3858

Child Protective Services investigates claims of the abuse, neglect, or exploitation of all children, including children with disabilities.

800-552-7096

Appendix VI: Attorney Experts in Justice Issues

You may want to consult with attorneys who practice in this field frequently in Virginia or out of state for ideas on defense strategies they have used, composition of justice plans, and who was part of their defense team.

Melissa Heifetz, The Arc of Loudoun

Melissa was a huge part of the inspiration for this guide. She is barred in New York, but now lives in Loudoun County. She has worked closely with The Arc of New Jersey and helped with the development of personalized justice plans.

<http://www.paxtoncampus.org/contact-us/>

Juliet Hiznay

Juliet is a Special Education attorney who has seen increasing and disturbing links between our schools and a pipeline to prisons. She worked on HB1213 that allows school documentation to be introduced as mitigating evidence in some school-based offenses.

<https://jd Hiznay.com/>

Sheila Costin, Holmes Costin Marcus

Sheila is a Virginia attorney who also practices in Maryland. She worked closely on the high profile defense of Reginald “Nelli” Latson, a man with autism who was waiting outside a library when police approached him after being misinformed about him having a gun.

<http://hcmlawva.com/sheila-costin.html>

Mark Mahoney, Harrington and Mahoney

New York attorney with expertise in individuals with autism who are high-functioning and accused of criminal offenses. He also has a number of publications.

<http://www.harringtonmahoney.com/mark-j-mahoney>

Melinda VanLowe

Melinda is a Virginia attorney with experience in both educational issues and criminal charges. She has worked with a large number of families whose children have been caught in the school to prison pipeline.

<http://www.vanlowelaw.com/>

Appendix VII: Special Attorneys and Advocates

Special education advocates and attorneys are privately hired support persons for those who feel they need assistance navigating the Special Education process. You can hire these individuals to consult on questions, attend IEPs, research and navigate on your behalf, and answer questions about local, federal, and state requirements for Special Education. Attorneys are able to bring a lawsuit against the school if you determine that is the appropriate course of action. Their services are generally more costly than those of advocates.

Attorneys

Juliet Hiznay
<http://jdhiznay.com/>
(202) 352-8982
juliet@jdhiznay.com

Cheri and Harold Belkowitz
<http://www.belkowitzlaw.com/>
10427 North St., Suite 200
Fairfax, VA 22030
(703) 246-9270
CBelkowitz@belkowitzlaw.com
HBelkowitz@belkowitzlaw.com

Brownley Law Group
www.brownleylaw.com
11710 Plaza America Drive,
Ste 2000
Reston, VA 20190
(703) 758-5562
info@brownleylaw.com

Advocates

Lisa Fagan
<http://www.lisafaganlaw.com/>
(571) 331-5626
fagan6@cox.net

Sharon Weiss
<http://www.sharonkweiss.com/>
6832 Old Dominion Drive
Suite 200
McLean, VA 22101
(703) 356-5534
sharonkweiss@cox.net

Connie Lorenzen
(571) 309-3787
Connie.lorentzen@gmail.com

Starfish Savers
<http://www.starfishsavers.com/>
PO Box 230636
Centreville, VA 20120
(703) 631-9557
info@starfishsavers.com

Appendix VIII: Attorneys for Legal Authority

These attorneys can assist you in obtaining Powers of Attorney, Conservatorship (limited, full, or temporary), and Guardianship (limited, full, or temporary).

Loretta Williams

Hale Ball
10511 Judicial Drive
Fairfax, VA 22030
(703) 962-1164
lwilliams@haleball.com

Kelly Thompson

6045 Wilson Blvd, Suite 101
Arlington, VA 22205
(703) 237-0027
Kelly@KellyThompsonLaw.Com

Ed Zetlin

2921-A South Woodstock Street, Arlington VA.
22206
(703) 379-0442
ed@zetlinlaw.com

Bill Fralin

Estate Planning & Elder Law Firm
2200 Clarendon Boulevard, Suite 1201
Arlington, VA 22201
(703) 243-3200
wsf@chroniccareadvocacy.com

Appendix IX: Providers of Psychological Evaluations

Northern Virginia-based resources for private psychological evaluations are below. Sometimes insurance will cover the cost of these evaluations. You can always start by contacting your insurance company to see if they have covered providers.

George Mason University Psychology Department, 703-993-1370 or 703-993-4200
Associated Clinical Services, 703-569-8731
Ashburn Psychological Services, 703-723-2999, <http://www.ashburnpsych.com/>
Behavioral Care Services, 703-398-1085

Appendix X: Behavioral Support Providers

If your loved one with a disability struggles with positive behavioral interactions, consider working with a behavior supports specialist. After age 6, it can be difficult to get this service covered by insurance companies (other than Medicaid). The following are providers of behavior therapies who can help with development and implementation of a plan to improve behavioral outcomes.

Developmental Support Associates

877-394-5106

<http://developmentalsupport.com/>

Little Leaves

202-420-8359

<http://littleleaves.org/>

Optimal Beginnings

301-718-1716

<http://www.optimalbeginning.com/>

Appendix XI: Circles of Support

A circle of support is a defined network of people who care about the person with a disability and want to play a role in helping them be successful. There are resources below to learn more about circles. It is a rich and growing subject area. The more you search online, the more you'll find. Check out <http://communitytze.com/> as a great resource for building your circle.

COMMUNITY DRIVE INC.

CIRCLE RESOURCES



Building Community through Circles of Friends

<http://www.learningdisabilities.org.uk/>

"A practical guide to making inclusion a reality for people with disabilities"



Circles Network has developed extensive expertise in the development of Circles of Support, Individual and Collective Advocacy, Person Centered Planning and Life Building.

<http://www.circlesnetwork.org.uk/>



This book offers a way of thinking about the critical issues affecting individuals with significant disabilities as their parents age and eventually pass on. From the Planned Lifetime Advocacy Network (PLAN), which supports families in British Columbia in building lasting circles of support for their family members who have significant disabilities <http://plan.ca>



Works with people and organisations to achieve person-centred change. <http://www.helensandersonassociates.co.uk>

Appendix XII: Medicaid Waivers

What is a Waiver?

A Waiver is a long-term support system for someone who will have long-term care needs, including someone with a developmental disability. Once you're awarded a Waiver, you will have access to a menu of services offered by your Waiver. Frequently used services include attendants who work one on one with the person with a disability, respite care so parents can have a break from care provision, group home supports where a person with a disability lives in a home shared by other people with disabilities, long term employment or meaningful day services, assistive technology, environmental modifications, nursing, and more. These services are offered at no or very low cost.

Who Needs a Waiver and who is Eligible?

People who need assistance with taking care of themselves, managing their environment, or maintaining a job because of a disability should consider Waivers. It is the only public funding for long term developmental disability supports. You will need a clear developmental disability diagnosis and IQ score to apply. This testing often comes from a licensed psychologist (through school, insurance, or private pay) and should be no more than 3 years old. If you're over 22 when you first get diagnosed or when you re-do testing, you'll need to show documentation from before age 22 indicating a disability was present (e.g., an IEP, statement from a doctor). You'll also need to show that you need functional help with daily activities and meet financial eligibility to apply. Details on these topics are also in this handout if you keep reading.

What are the Types of Waiver?

We'll overview the three Disability Waivers (Community Living Waiver, Family and Individual Supports Waiver, and Building Independence Waiver) as well as the Elderly or Disabled with Consumer Direction (EDCD) Waiver because they are the most common Waivers for people with developmental disabilities.

The three Disability Waivers are a continuum of services for people with developmental disabilities. The Community Living Waiver is aimed for the minority of our population who have extremely high medical, behavioral, or support needs and provides 24/7 active services. The Family and Individual Supports Waiver is the Waiver for the majority of people - those who need supports for between a few hours and most hours of the day, including overnight monitoring in some cases. The Building Independence Waiver is for people who can live and work with a fair amount of independence, but need drop-in supports. People utilizing the Waiver are assessed every three years with a test called the Supports Intensity Scale (SIS) to measure the intensity of their needs. People with more needs receive a higher reimbursement rate for some of their services.

People can move between these three Waivers if their needs change over time. Moving to a Waiver that serves people with higher needs may sometimes involve a waiting period.

The EDCD Waiver is for people who have a developmental disability or are over age 65 and have significant medical needs. Its services are primarily attendant and respite care, and some nursing for people under age 21.

Disability Waiver Services		Community Living Waiver	Family Supports Waiver	Building Independence Waiver
*Available with EDCD Waiver				
Residential	Group Homes- 24/7 staffed home where 3-7 people with disabilities live. Homes usually have staff that rotate around the clock on shifts.	X		
Residential	Shared Living- Individual lives with someone without a disability who is reimbursed for room and board in exchange for companionship	X	X	X
Residential	Independent Living- Supports brought into the home focused on skill building and preparing for greater independence			X
Residential	Sponsored Residential- Option where person with disability lives with a paid caregiver in the home of the caregiver	X		
Residential	Supported Living- Residence owned by a support provider that offers up to 24/7 help with support needs	X	X	
Day & Employment	Community Engagement- Service to improve skills for employability and independence using the community as the environment	X	X	X
Day & Employment	Supported Employment (Group and Individual)- Supports on the job to allow people to work in competitive employment	X	X	X
Day & Employment	Day Support- Either center or community based supports that are typically unpaid and involve skill development	X	X	X
Day & Employment	Workplace Assistance Services- Services for someone who needs to fill the gap between initial job training and following along services	X	X	
Day & Employment	Community Coaching- 1:1 support to build a specific skill or break a barrier to employment and community engagement	X	X	X
Day & Employment	Benefits Planning- Services to help individuals receiving social security benefits understand the impact of work on those benefits	X	X	X
Disability Waiver Services		Community Living Waiver	Family Supports Waiver	Building Independence Waiver
In Home	In-home Support Services (up to 24/7)- 1:1 services in the home focused on life skills	X	X	
In Home	Companion Services*- 1:1 fellowship and monitoring	X	X	
In Home	Respite*- Supplemental annual hours of personal care to provide relief to the unpaid caregiver	X	X	
In Home	Environmental Modifications- Up to \$5000 per year to modify a primary home or vehicle	X	X	X
In Home	Personal Emergency Response System- Electronic safety monitoring system linked to emergency services	X	X	X
Community Supports	Electronic Home-Based Supports- Support items to be used in the home for greater independence in lieu of paid staff during some hours of the day	X	X	X
Community Supports	Assistive Technology- Up to \$5000 per year on portable items to assist with independence/safety	X	X	X

Community Supports	Crisis Supports (center and community based) - crisis prevention and stabilization	X	X	X
Community Supports	Community Guide - Direct assistance in promoting and developing community relationships that promote integration and self-determination	X	X	X
Community Supports	Non-medical transportation - Reimbursement for transport to locations associated with an individual's support plan and goals	X	X	X
Medical	Private Duty Nursing* - 1:1 continuous care nursing for people with complex medical needs	X	X	
Medical	Skilled Nursing* - Intermittent nursing	X	X	
Other	Therapeutic Consultations - Limited consultations with therapists in qualifying areas	X	X	
Other	Transition Services* - Funding and supports to assist people with leaving institutional settings	X	X	X
Other	Individual and Family/Caregiver Training - Training on disability needs for primary caregivers		X	

How is This Funded?

Waivers are funded by Medicaid and are often called Medicaid Waivers. The person with a disability must qualify for long-term care Medicaid to use a Waiver. As of 2016, this means that the person with a disability cannot have more than \$2,000 in assets in their name (\$1,000 cap if under 18 years old), unless those assets are in a Special Needs Trust, and they cannot earn more than \$2,199 per month. The person with a disability will get Medicaid once they get a Waiver. They can use that Medicaid as a supplemental health insurance if they like, or they can drop their other insurance coverage and only use Medicaid if they choose.

Why Should I Apply?

Anyone with a developmental disability who needs daily support should apply. Even though some Waivers have waiting lists, if you qualify for a Waiver, you will eventually receive services. As you grow and change, you can use more or fewer Waiver services to meet your needs. The Waiver should grow with you over time and provides the supports you need to be as independent as possible in your community.

Also, as a result of a Department of Justice settlement agreement with Virginia in 2012, if you're on the waiting list for either an ID or DD Waiver, you can apply for up to \$1,000 each year to purchase supports you need to be independent and safe. This is called the Individual and Family Supports Program.

How Long is the Wait?

The Disability Waivers have a combined waiting list based upon urgency of need. People in Tier One of urgency need services within the year, people in Tier Two need services in 1-5 years, and People in Tier Three need services several years out, but are planning ahead. The list shifts constantly as situations change, so you should be in touch to share information about your urgency as it changes with the group that put you on the list (more in the chart above).

The EDCD Waiver has fewer services, but no waiting list at all. About 1/3 of the people on the Disability Waiver waiting list also qualify for the EDCD Waiver and use it while they wait to receive some supports.

Appendix XIII: Private Job Coaches

These Northern Virginia agencies can help individuals find and maintain jobs that will promote independence and prevent further criminal involvement.

Next Level Transition Consulting
571-332-2992
<http://www.nextleveltransition.com>

SPARC
703-338-6185
<http://sparcsolutions.org/>

Service Source
703-461-6000
<http://www.servicesource.org/services-by-state/virginia>