

Changing the way we support people

By

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Introduction:

After finishing high school, my son and a friend left for an extended trip to Europe. Alex spent the next several months travelling around Europe enjoying life in several different foreign countries. Alex and Robin traveled mostly by train and stayed at youth hostels, low-cost hotels and with friends. They found ways to eat cheaply, but still enjoy the local cuisine.

Alex and Robin enjoyed life in a variety of different foreign countries that they traveled in. They spent most of their time in Germany, France, Austria, England, and Ireland. Spending winters in Nice camping on the beach in order to save money or enjoying Halloween eve in London visiting all of the sites that Jack the Ripper killed his victims seems like an interesting adventure to take if you are a young person. Alex and Robin met lots of local people who welcome them into their country and at times into their homes. They showed Alex and Robin around their country and developed friendships that have lasted many years after the journey ended. Alex and Robin really enjoyed visiting all of the traditional places one would normally visit as well as unique and different things to see that many tourists never get to visit. Of course, being young people they really enjoyed the nightlife of each of the countries they spent time in and did spend a lot of time getting into that night life.

Upon returning to the U.S., Alex and Robin decided to travel throughout United States. They started visiting different states throughout the nation at different times of the year. They wanted to experience being in Kentucky on the first Saturday in May so they could be in the infield during the Kentucky Derby or in the bleaches during the Indianapolis 500 in late May. If it wasn't the infield in Kentucky or the bleaches at the 500, it was camping in Oregon, whale watching in Washington, visiting the Grand Canyon, enjoying life at the Commons in Boston, etc. Alex and Robin wanted to see lots of different things throughout our country and just enjoy life.

Ultimately, Alex went to work for a large fast food restaurant for several years, lived with different roommates, attended community college to become an auto body tech mechanic, and continued to travel. Several years

later, he moved into the mountains outside of Santa Cruz (CA). He lived in a great house with large trees in the front yard in a great neighborhood. He worked part-time as a laborer doing construction. He has lots of friends and other connections in the community. He enjoys being a regular at an English pub in Boulder Creek or going to summer concerts on the beach in Santa Cruz. Life is good. Life could always be better, but it is not too bad. It is a life that is filled with exciting moments and normal routines and rhythms.

Alex has Down's syndrome, intellectual disabilities, and profound hearing loss! For most people with developmental disabilities transitional planning usually has meant moving into a sheltered workshop, enclave, work station, or mobile crew and then living at home with your parents or moving into a group home or residential facility. If you got very lucky maybe someone mentioned supported employment and once in while supported living, but not very often and not if your needs were viewed as "more intense." People with developmental disabilities did not have the same opportunities as their non-disabled peers to experience a wide variety of options after graduating high school and moving into the world of adulthood.

So, why is this training event so important? It attempts to break out of the traditional way of thinking that most stakeholders involved with planning have found themselves in. It attempts to get people out of the boxes we normally place people in when thinking about the possibilities for the future. It further attempts to help us think creatively about all of the opportunities for people to take on their unique personal journey through life. Whether it is going to work, starting your own business, going to college, traveling, buying a home of your own, getting married, or whatever doesn't really matter. What does matter is that all of these options should be available to all people. Not just some of the options for some of the people, but all of the options for all of the people to choose whether they want to pursue one journey or another.

This decision-making should not be based on the perceived skills and competencies that an individual might possess or that an official "test" may indicate is the way to go for a specific person. What we need to see is for all people to have all options available to them as they move forward with their personal journeys. Then people will need to determine where they want to go and hopefully they have lots of people around them to advice them and at times guide them on their journey.

For far too many families, dreaming about desirable futures does not come easily. People with developmental disabilities and their families have not been either allowed to dream about new and exciting possibilities or have been limited in what they could even envision was possible to dream about. This training event provides an opportunity for families, consumers, and those involved with supporting people to start planning to think of new and different options for each person.

To ask the question, what do you want to do with your life and how can “we” support you to figure this out seems like a question that is well worth asking. It is also more important to ask people with developmental disabilities and their families what they want to in life and not just ask professionals what is available. Our job is to support not lead or direct people’s future. For most families and people with disabilities, these questions never get asked. A limited set of options, mostly very traditional, are usually offered as the only available options. The more “disabled” you are perceived to be the less options available to you and your family.

What is very exciting about this training event is that it attempts to help all of the stakeholders who are surrounding the person with a disability to think more creatively about the range of possibilities. This training event attempts to help us to think outside of the “box.” It forces us to learn to listen to people more deeply and to honor their dreams and visions. It also will help us realize the importance of providing support and assistance to people so that they can move closer to living their dreams out on a daily basis. It further helps us learn ways to figure out how to plan and design supports so that people can enjoy a valued wonderful life in the community.

There are no simple gimmicks or short cuts to learning to listen, getting to know people, and figuring out what people want to do with their lives. While there are no simple magic bullets there are tools that can assist. There are also strategies that will assist us to move closer to helping people figure out the transitional needs of an individual. This training event is a good start in achieving both of these goals.

For far too long, our assessment tools and strategies did not really look at creative and thoughtful ways to support individuals, especially people with higher support needs, to have a good life. Most of these assessment tools and strategies placed the blame on why people didn’t have a good life strictly on them. It was the person’s fault. If they would only learn, get their behaviors

under control, if they just didn't cause problems, etc. then people would be able to earn their way into a good life. We blamed the victim on why their lives were not better. We used "official protocol" that allowed us to reject people from thinking creatively and pursuing things that were important to them. We were able to stand behind our professionalism to confidently tell people why they would never accomplish a certain goal or achieve a desired outcome. It was a safe place for many of us to be.

At the same time, many people, which included parents and professionals had relegated people with disabilities to a low status and with very low expectations. Low status and low expectations became a self-fulfilling prophecy. People with disabilities led marginal, miserable lives. They were rejected from the "mainstream" of life in the community because of their disability. Of course, we were happy to donate our used items to them, but to see people with disabilities as contributing, valued members of our community was not on the radar screen.

Organizational Change at Jay Nolan Community Services

For the past thirteen and half years, Jay Nolan Community Services has been working to transform itself from being a large human services agency providing traditional services and programs to people with autism and other developmental disabilities to an organization who provides an array of services in individualized and personalized ways so that people can live valued lives in the community. Our journey will never be over. We will continue to struggle to provide the right support provided by the right people at the right time in the right manner and to do that consistently. However, we have taken several very positive steps over these thirteen and half years to move us closer to meeting the unique needs of each and every person who comes to our front door.

Overview of JNCS

Jay Nolan Community Services is a not-for-profit human service agency supporting people with autism and other developmental disabilities to live valued, lives in the community. Jay Nolan was founded in 1975 by the Autism Society of America—Los Angeles Chapter. Our Board of Directors is made up of parents and other family members who have "children" with developmental disabilities.

Jay Nolan Community Services provides supports to individuals in three distinct areas. These areas include:

1) Supported Living – our organization assists people to live in their own homes with whatever level or intensity of support and assistance that is required in order for the person to be successful. This may range from support provided 24 hours per day to only several hours per week. On average, JNCS provides support to people with higher support needs (people who require 24 hour per day support). No matter what level of support is required people can live in their own homes. Certain skills, behaviors, or whatever is not needed for people to live in their own homes. Secondly, being in the community and being a part of the community is not the same. We do not want the people we support to just be physically present in the community, but to be connected to the community, its people, and life in the community.

In the past, JNCS administered group homes (four, five or six people with autism living together). In 1992, this way of supporting people with autism and other developmental disabilities did not make any sense. It was not person-centered. Therefore, JNCS moved away from group homes to supporting people in their own places one person at a time in their own homes. It took two and half years to close thirteen group homes and to moved 65 people out to their own homes.

Today, JNCS supports 92 people in 90 different homes of their own with a variety of different supports and assistance.

2) Personalized Day Support/Supported Employment—our organization believes that all individuals can and should work in integrated, paid jobs if the support was provided in the intensity, duration and frequency that it is needed. If people do not work, then they will attend college classes, volunteer, participate in leisure/recreational opportunities, etc. Our PDS/LINK (Personalized Day Support program or LINK day program) will provide whatever assistance is needed in order for people to spend their days in valued ways and not to be subject to day-wasting programs (day behavior management programs).

We continue to struggle to provide valued work opportunities for all of the people we currently serve. While we closed the day centers, trying to

identify and support people to work and do other valued activities that really make sense continues to be a challenge we face on a daily basis.

3) Family Support Services—our agency provides an array of supports in order to keep families together including but not limited to adaptive skills, camp, support in integrated situations for same age peers (supporting children to attend the local Y, church play group, etc.). Family Support services may include both intensive support provided twenty-four hours per day, seven days per week or just a few hours per week in order for families not to break up and for children not to be removed from their home. It is also our intent to help children to be connected in the community to non-disabled peers and to access generic activities in the community.

However, in some rare situations, children can not live with their birth families even if intensive supports are provided. In those unique situations, JNCS assists with locating Foster families to provide support and assistance to the child.

Authentic Choice: Myths, Excuses and a deepening understanding of choice

Choice is something we all care about. Choice is one of those attributes that most of us will not easily give up. We love to have choice of what we eat, where we live, what we do with our lives, and so much more. Choice is something we yearn for and we will fight to maintain. Choice allows us to explore new and different adventures in our lives. Choice allows each of us to show our individuality and better learn who we are.

Choice is complex and messy. Sometimes we do not get a chance to choose exactly what we want because there are pressures placed on us by colleagues, friends, family, money constraints, responsibility, etc. that prohibit us from choosing one option over another. No matter how complex and messy choice might be, we struggle each and every day to deal with this issue in better ways. We try to learn from our mistakes about the bad choices we have made in the past and choose better choices in the future. We look for new ways to understand and negotiate the choice process.

However, choice has been used to exclude and prevent people with autism and other developmental disabilities from having a quality life. Choice has

been a vehicle to allow people to be hurt, removed from society, deepening their wounds and vulnerabilities and so much more. People who do not speak or are not easily understood have others making their choices for them. If it is not a parent or family member making the choice then it is someone in a professional role that makes the choice for the person.

Choice has been used historically as a reason for segregated and congregated programs. Choice has been used a reason for restraints, punishment, seclusion, deprivation, coercion, and again so much more.

Some of the myths that have been used to prevent people from living the type of lives we would want to see happen for them include but are not limited to the following:

- 1) People are safer in segregated programs. While safety is important and a valid concern, we must recognize that none of us are truly completely safe in our society today. We all experience to some degree the day to day challenges of living in the community and trying to remain safe, but still live our lives. However, according to Dr. Dick Sobsey, University of Alberta, the more segregated you are the more likely you are to be abused, neglected and victimized. Safety is more likely to happen when people are in the community, connected to friends, associates, allies, and others. Safety happens when people with disabilities have had experiences, information, training, and coaching to deal with all of the challenges in front of them.
- 2) People choose segregated programs. While it is true that some people for some parts of their lives choose segregated programs – boys night out, fraternity living, young republicans, women only gyms, etc., it is only for a small part of their overall day. The key is that all people need to have all available options open to them. People also need to realize that they will receive the support and assistance that is needed to be successful in a new environment.

If the only recreational program that is available to you is Special Olympics then that is what you may choose. That is neither fair nor right. If you have lots of options and then choose to be involved in

Special Olympics then that is very different. However, people with intellectual disabilities have not had the chance to hang glide, white water rafting, canoeing, etc. Unless you have been provided with opportunities, coaching and support, you may have had only a few options open to you.

- 3) Segregation is cost-effective. Resources are scarce and therefore, it is cheaper to house/group people together. We have used money or the lack of money to deny people choice and control in their lives. We have told people that real community options are more expensive, but the reality is that most segregated programs have a very high cost because of the inherent nature of these programs. When one realizes both the long term as well as the short term costs associated with segregated and congregated programs, you realize that the costs are way too high. You also need to conduct an analysis of the cost-benefit of doing or not doing things. Sometimes we forget that spending more money initially will reduce your long terms costs over time.
- 4) Segregation is a part of the continuum of services. While this concept comes from a legal framework (least restrictive environment) – it has legalized the notion that segregation is both permissible and legal. It is also the wrong question – we should not talk about the least restrictive environment, but the environment that has the most potential of growth, development and inclusion. Which environment offers the real opportunities for a valued and desirable life?
- 5) People can only learn things in a segregated program that they will need to know before going into the community. This concept entitled “readiness” training is completely wrong. There is nothing that can be taught in a segregated program that could not be taught in a regular inclusive environment. However, there are certain things that can only be taught in an inclusive community environment. Learning things is important and something we should work on, but learning what is important and useful so that you can live in the community can only be taught in the community.
- 6) There is a myth that you can’t trust the community or its members. We need to protect people with disabilities from the community and its members for their own benefit. The community is evil and will take advantage of people with disabilities. The community is a

complex environment. It is not perfect. It has its flaws that are for sure. But the only way we are going to figure out how to live with one another is by living with one another on a daily basis.

- 7) There is the belief that if you go out on outings on Monday, Wednesday and Friday for two hours you are in the community. Or if your facility you spend the majority of your time in is physically housed in the community – hence it is a community program. This is non-sense. Like pregnancy you are either pregnant or not – you can't be partially pregnant. You can't be in the community only on MWF but segregated away the rest of the time.
- 8) There is a belief that inclusion and integration is a value and that a similar value of segregation has equal weight. I do not believe this for a second. There are certain values, beliefs, philosophy, etc. that are not open for discussion. The Supreme Court in the U.S. stated “segregation can never be equal” in the famous Brown versus the Board of Education. Inclusion should not be seen as good or bad. Inclusion should be viewed similar to Tuesday. Some Tuesday's are better then others.
- 9) One of the myths that people have used to prevent people disabilities from living full lives in the community is the fear that people will be more isolated, lonely, and at risk. All people are at risk of being lonely and isolated. This raises the important question around good support, good planning and eternal vigilance. We must always be aware that any good idea has the seeds of perversion in them. It is further true that there is turn-over in support people in the community and this is a real challenge. But at the same time, there are many wonderful examples of people sharing their lives with folks over extended periods of time. The key is the matching people, building people's circles, and helping people to be connected to their community.

What currently passes for being in the community: walking the malls, parks, zoo, beaches, and food court is not being in the community! It is wasting people's time!

You can't go out into the community these days without seeing people with disabilities in a small group of three, four or five wandering around the malls, sitting in the food court, going to the same museums, zoos, parks, and other places where people can spend their time. These experiences have passed as being in the community or community-based programs. While there is nothing wrong going to the mall (you have to buy a gift for your sister for her birthday), or taking an hour out of your day to walk around the lake in order to get some exercise, these are not the primary reasons organizations have used these places.

The primary purposes are: a) people have no money and hence these are cheap ways to spend a day, b) the lack of creativity on the part of staff, families or the person have led to these type of options, c) more innovative options have been rejected because of the person's severity of disability, group ratios, or transportation problems such as work in paid integrated employment, attending university, volunteering, etc. and d) low expectations – she is not even toilet trained what else can we do?

While all of these issues have some level of legitimacy they are not valid reasons for keeping people housed in our day programs. These activities have led people who support facility – based options to cry out – why would we want our people out of the shop doing mall walking. This is absolutely an accurate concern. While the facility- based model is not appropriate, we can no longer accept low expectations on what people should be doing during the day.

It is time to take the position that if you are between the ages of 18 – 65 you should be working in a paid job in the community alongside non-disabled people for at least “x” amount of time each week. The remainder of the week you can spend time volunteering, looking for a second job, learning something interesting at school or university, etc. However, the primary focus should be on paid employment. Obviously, if someone is interested in owning their own business as another option that could be a part of someone's week as well. But unless you are Paris Hilton and have parents and grandparents with lots and lots of money, you should be working!

The key issue is that people with disabilities need to be doing things during the day that enhances their status and reputation. People with disabilities need to have organizations, family, staff, and other stakeholders urging, encouraging, etc. people to move forward and do things that have value. The

only reason someone goes to the mall is to purchase something or comparison shop or meet someone for a quick lunch. There is nothing wrong with even mall walking, but then that is done either very early in the day to get some exercise or from time to time on a weekend.

In order for people with autism and other developmental disabilities to use choice to expand their horizons and opportunities, people may need to think about the following:

- 1) Choice must be done in the context of people who will stand with you and walk with you on your personal journey over time. Many of us require a circle of friends or support to make decisions in our lives and then for that same group to advice and counsel us. Ultimately, this same group may need to provide support and assistance to us as we pursue the choice we have made and from time to time even pick us up when we falter.
- 2) Informed choice assumes you have had the opportunity to practice choice making over time. This starts with families and young children. Did we have a chance as a youngster to make small choices and then with practice expand the choices you were allowed to make? With time, you are making greater and more complex choices. You can't assume people can make major choices after years of making no choices at all. People need practice, coaching, and opportunity.
- 3) Choice assumes that the person who is making the choice is competent. The problem is we believe that there are people who are not capable of choosing because we perceive them as incompetent and not intelligent. Whether that is true or not, is another story. I would suggest that we assume competency for all people rather than take a deficit look at people's lives.
However, each and every one of us has made bad, foolish, and gross mistakes in our lives. We have eaten the wrong foods, not exercised, bought something we should have not purchased, etc. While mistakes are fine, if people with intellectual disabilities make a poor choice then we hold that against them for the remainder of their lives and they have to prove they are able to only make the right choice that we believe is right in the future in order to regain the power to make any choices.

- 4) Good choices are made when people receive good support. If people are not receiving the support they need or require, they may not be able to make the best choices they could have made.
- 5) We have talked about before, but choice assumes that is ok to make an error or mistake. Nobody makes 100% perfect choice all of the time. People with disabilities will make as many good or bad choices as any of us.
- 6) There are certain choices that our society has indicated are not acceptable. You can not reject medical treatment for your child based on your religious beliefs. You can't hurt your child because that is how you were brought up. You can't have sexual relationships with children and use the excuse that this is some sort of religious ceremony or you love each other even though you are 30 and the child is 14.
- 7) Choice must always be thought about in a larger context. Choice is one of the key traits we all care about deeply. However, choice must be thought about in terms of our larger societal views. While segregation may be an important concept for some situations (prisoners) our community has a right to say all children will learn together. All adults have the right to live next door to you. We choose as a society that different ages, genders, cultures, disability groups, etc. should live alongside each other and that our communities are stronger when diversity takes place. Others may want to eliminate diversity as a variable when defining a good community. I think the majority of us would say that is wrong.

Conclusion:

Times are indeed changing. People with disabilities including people with very high support needs are taking the rightful place in our society as contributing and exciting members of our community. It is neither easy nor simple. Things do not work out the first time perfectly. However, we are seeing throughout our world a change in the way people with disabilities experience life in the community. This training event will continue to assist the different stakeholders involved in planning with better understanding people with disabilities and how to support them to transition to a new

exciting adventure in their lives. Equally important will be changing the behaviors of the different stakeholders who are involved with transitional planning which will allow all people especially people with higher support needs to truly experience the transition from teenager to adult with excitement and passion.