Texas Autism Research & Resource Center

TARRC

The Texas Community Assessment and Planning Toolkit for Autism Services

"*When people … begin to feel really met and understood in this way, they may begin … to connect with their own inner creative resources in a way that leads naturally towards the resolution of problems and difficulties …" – Chris Neill and Tamsin Cottis*

TEXAS
Department of Aging
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Executive Summary

Welcome to the Texas Community Assessment and Planning Toolkit for Autism Services (CAPT). This resource was developed to help community leaders assess and, where necessary, plan to improve the way communities welcome people with autism and other disabilities, as well as identify how those people contribute to their communities. A primary objective of CAPT is helping communities to ensure they provide effective and adequate services and supports to individuals and families affected by autism spectrum disorder (ASD).

Community change is complicated because, although all communities share certain factors, they are unique. Lasting change comes with passion from within the community. Communities are more successful when they pursue a new future – a focus on what is possible – as opposed to merely reacting to problems.

This toolkit incorporates concepts from organizational development, such as the Six Conversations in Peter Block's work (see Readings). It also uses business strategies, such as the role of the Champion, and draws from social work and other models for community change. In addition, it incorporates the role of government as resource and active partner to bring about a community's vision for the future. Through creating a real dialogue with governmental agencies, strong partnerships can be built that help to move forward community objectives.

This toolkit addresses how communities can adapt to welcome their members with autism and other disabilities. From this perspective, it is important to keep in mind throughout this process that a person with autism is just that – a person who happens to have autism. People with autism rely on and are involved in their community for the same reasons as everyone else: as a customer, as an employee and as a participant.

CAPT is open-ended, with a planning model that encourages users to develop a shared vision, remain open to the ideas of others, incorporate multiple perspectives, be thoughtful about the future, and develop a meaningful plan of action.

In short, CAPT takes the power of commitment and belief in change, and knowledge about how change takes place in organizations and communities, and puts them in the hands of community members with the strongest interest in making daily life better for people with autism and other disabilities.

Introduction

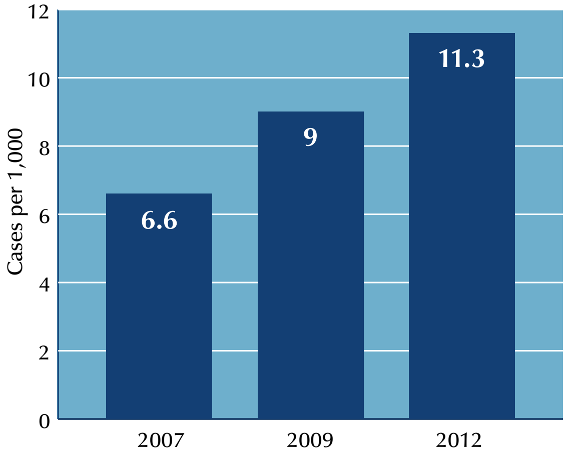
In late March 2012, the Centers for Disease Control and Prevention in Atlanta announced an autism prevalence rate of 1 in 88, based on data from a comprehensive 2008 study. This represents a 25 percent increase from estimates reported in December of 2009 based on data collected in 2006 and a 71 percent increase from estimates reported in February of 2007 from 2002 data (see graph).

These rates are alarming; at the same time, it is unclear why they are increasing. Do these jumps reflect actual increases in the incidence of ASD? Do they indicate better diagnostic practices, greater awareness, or are we to assume trends of over-diagnosis? Likely, the answer is that it's a little of each.

Despite everything we don't know, one thing is certain: Policy makers have a challenging road ahead of them as the public calls, increasingly loudly, for a comprehensive agenda on ASD.[1]

According to the 2009-10 National Core Indicators[2] estimates, a national survey used by the Texas Department of Aging and Disability Services (DADS), about 10.5 percent of the population of people with developmental disabilities served through DADS had autism. This is slightly more than the national average of 10.3 percent. These estimates prompt DADS to strive to be a national leader in supporting Texas citizens with autism and other disabilities, through actions such as seeking federal grant money to expand existing programs and create new ones, and by continually evaluating existing programs for cost-effectiveness to stretch existing funds and serve more people.

Prevalence of ASD



Policy makers routinely work to involve communities when they plan for people with disabilities. It is helpful to gather suggestions and input through stakeholder surveys and focus groups. However, it can be challenging to accomplish lasting partnerships with communities. Government agencies must implement policies set and funded by the legislature, and policy makers and government can't do it all. For example, while DADS spends some $6 billion every year to provide needed supports, government resources can't meet every

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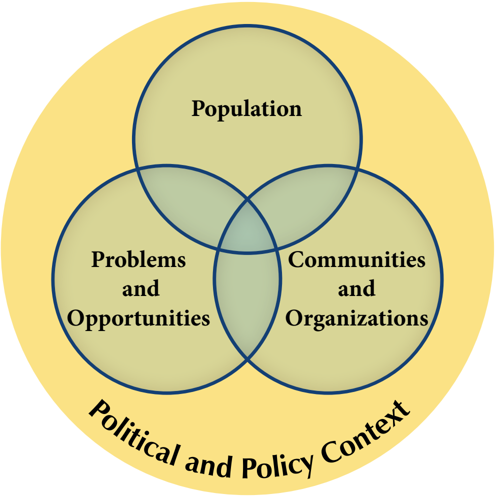
[1] *The Center for Disease Control and Prevention, http://www.cdc.gov/Features/CountingAutism/*

[2] *National Core Indicators Project, http://www.nationalcoreindicators.org/states/TX/*

need. Communities must also play a role in guiding their own destinies, and people must take personal responsibility.

People with ASD live in communities and need their support. How can communities make real change in partnership with government (which can't do it all) to the benefit of people with ASD? CAPT is designed to do help do just that.



Adapted from Netting, F.E. Kettner, P.M., McMurtry, S.L., & Thomas, M.L. (2012). Social work macro practice. Upper Saddle River, NJ: Pearson.

As the bubble diagram shows, community emerges from a group of people addressing problems and taking advantage of opportunities through organized responses. Businesses are part of this process, as are schools, clubs of various kinds and houses of worship.

Garnering support for change from community organizations such as advocacy groups and trade associations is not enough. These organizations have a role to play, but they cannot take the place of the larger, more diverse community that is needed to implement substantial change. So it is important to support entire communities in assessing how community life is for people with ASD. Based on their findings, they can then plan real and lasting change.

True change happens when the community takes responsibility for its own well-being and the well-being of its members, including members with disabilities. This kind of organic response occurs independent of government but still contributes to larger policy goals that emphasize quality of life, inclusion and access.

This toolkit provides support and assistance to communities as they work to make real and lasting change.

Creating Community Change

Communities of all kinds all around the world grapple with change. Urban communities struggle with problems of crime, blight and safety. Small communities struggle with economic development, access to services and growth. Fortunately, a great deal has been learned through studying communities' efforts to create meaningful change.

Two things emerge as basic principles that are essential to creating real and lasting change in a community. Commitment is the most essential element of change. It is internally driven and, with true commitment, progress is made even if other things, such as funding, are lacking. Without it, infinite resources and funding will not make lasting change. Second, community change rarely happens from the outside, especially in quality-of-life aspects such as safety. For example, outside influences, such as federal or state funding, can provide the resources to build a playground, but how that playground is integrated or not integrated into community life is up to the community.

Community change is hard work, and many promising initiatives fail because some basic considerations are not addressed. This toolkit takes these nuts-and-bolts issues into consideration.

- **Time.** Community change must be internally driven, which means that the people involved are members of the community and have other things to do. Some may be housewives and mothers; others may be business owners or employees. To acknowledge that community members have limited time for extra activities, the CAPT process depends on very little work outside the meetings. If there is too much homework, the process will get stalled, and eventually community members will lose interest.
- **Expertise.** It is important for community members to avail themselves of expertise, especially when dealing with something as complex and nuanced as ASD. Some communities may have the luxury of having an expert as a member, perhaps a representative of state or local government or a provider of services. Other communities may not have that advantage. Further, it is important to remember that in solving community problems, expertise is useful but not essential. Many communities with concentrations of expertise close at hand still have problems. Again, if a tool like this is to be useful in a wide range of circumstances, it cannot assume the presence of expertise. Any tool that strives to support community assessment and planning must assume that a professional facilitator is not the best option for getting things done because not every community can afford such a person. Besides, in many cases, an outside party may not know the community well enough to guide certain tasks in the process. This tool was developed for community members with a vested interest to be able to accomplish the assessment process without the services of a facilitator.
- **The importance of being focused, yet flexible.** The challenge of any tool developed to assist with community assessment and planning is to be flexible enough to have the widest possible application yet provide a targeted framework; otherwise, the community runs the risk of missing out on real or useful results. For example, a tool developed specifically to help a certain suburb of Dallas can start with a lot of detail about that particular community. It may even start with the needs clearly defined. Developing such a tool will take a great deal of time and expertise, but it will not be very useful in a rural community or even Houston.

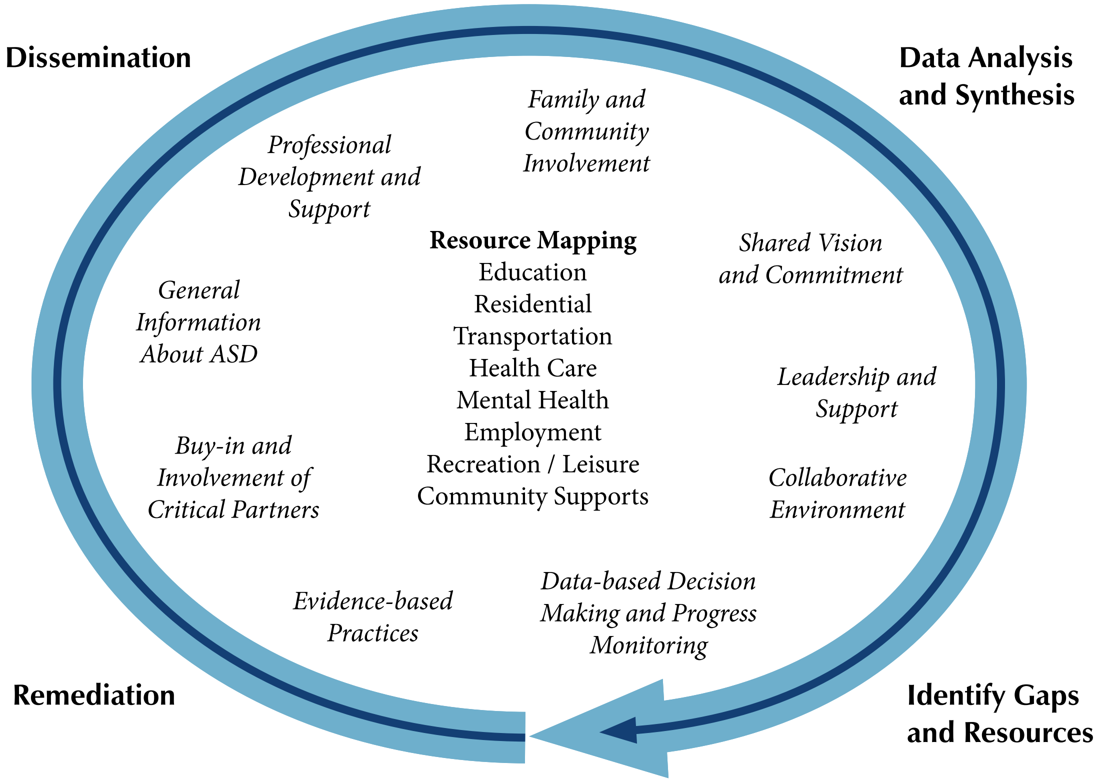
What's the Point?

The primary point of community action and development is to help the community become a better place for everyone to live, work and play. As mentioned, communities do better when they change themselves. To that end, commitment is the driving force. The best combination for change is passion and effective tools. With a specific target, such as "We need to improve safety in our neighborhood" or "We need to create jobs for our community members with ASD," and commitment behind the target, the outcome will be specific things for the community to do.

The process may also yield things the community thinks government should do, such as expand the capacity of a certain ASD-oriented service or develop programs to increase public awareness about ASD. These are important goals, but they are secondary products.

When the plan is complete, everything should be shared far and wide. The plan should be available to everyone. It is especially important that it be sent to state and locally elected officials and DADS. Sharing is critical so that a dialogue between the community and government over the issues presented by ASD can emerge. This dialogue helps government connect the needs of those with ASD with important domains of community life, such as work and recreation, and encourages long-term planning (see Community Planning Considerations in ASD). The dialogue also helps communities recognize the limits of government and identify where communities need to change their own situation and that of their members.

Community Planning Considerations in ASD



Community Members with Autism

This toolkit is intended for use in a wide variety of communities, from urban neighborhoods to suburbs to small towns, but its focus is on ASD.

Some of the services needed by people with ASD are very specialized, but people with ASD also need things everyone needs, such as medical services and occupational and physical therapy, to name a few.

This community assessment and planning tool may produce recommendations for action on the part of government, related to the specialized services many federal, state and local agencies provide (e.g., Medicaid waiver program services) to children and adults with ASD. However, your main focus is to identify how you can improve your community to make it a better place for people with ASD to live.

So we start by looking at the person with ASD as a member of the community, in many ways just like any other member of the community. This is a good perspective that will benefit everyone, because doing things as a community to help a small segment of the population always has larger positive impact. Think of curb cutouts, the little ramps cut out of the curb on sidewalks at intersections. We have these cutouts to make it easier for people who use wheelchairs to cross the street. They are revolutionary for people who use wheelchairs and have opened up endless possibilities for them in terms of accessing their communities. But in reality, people with wheelchairs don't use them nearly as often as kids on bikes or skateboards or moms with strollers or wagons do. Curb cutouts are a great idea that works for everyone.

When we start by looking at people with ASD as people, more like others than different from others, we are free to start thinking about what our community is for all of us. There are three basic dimensions to community life: access, communication, and socialization. Two of these dimensions happen to be significant areas of impairment associated with ASD, so our challenges may begin here. If you look at the practical activities or roles that dominate community life, however, opportunities emerge. The dominant roles that we all fill are the roles of earning, buying and participating. Now the questions of inclusion become clearer. How do we as communities make it easier for people with ASD and their families to become and remain earners, buyers, and participants?

- **Earners:** Getting and keeping a job, accessing education or training for employment, becoming contributors to the tax base.
- **Buyers:** Consumers with purchasing power who have access to merchants and buy the things they want and need, contributors to the local economy.
- **Participants:** Members of civic organizations, organized sports and recreational activities, book clubs, contributors to the social capital of the community.

This is the focal point of the Texas Community Assessment and Planning Toolkit for Autism Services. It does not replace the work of government programs or of specialized providers. But it does help communities to improve themselves for all of their members, including those with ASD.

There are other advantages, too. Consider employment. What if a community can get better at developing employment possibilities for its members with autism and other disabilities? Currently, the most common way people with significant disabilities, including ASD, get help in working is through sheltered employment. A recent study by researchers at Kent State University examined the economic impact of supported employment versus sheltered employment. Considering both costs, such as paying workshop staff, and benefits, such as increased tax revenue, they concluded that the average net gain to taxpayers for supported employment (instead of sheltered employment) was $251.34 a month across numerous disability types. For ASD, in particular, the net benefit per month was $290.10.3 Like curb cutouts, this works for everyone.

How Does the Toolkit Work?

CAPT uses a simple approach with a Champion to energize the process. The Champion is similar to somebody who plays a familiar role in the business world. This is the person in the company's management who really believes in the product and can help motivate doubters, identify opportunities, and help the development team cut through red tape. In this context, the Champion is the community member who really believes in the need for change. It may be a parent or a business leader. His or her passion and commitment are the batteries that charge the process and keep it going.

The Champion starts by gathering a team. The toolkit suggests who should be on the team and how to find a place for the group to meet. The Champion cannot do all the work, however. The toolkit itself does most of the work. It's designed that way.

It's important to know that the process described here has been designed to be time-limited. There are two major reasons why these kinds of projects typically fall by the wayside. First, they take too much time out of busy schedules and people have to wait too long before results emerge. The toolkit uses a "six meetings in six months" format with each meeting timed to last no more than two hours. This way, the process is not overwhelming yet stays on track to be completed in a timely manner.

The other reason why projects like this often fail is that they require too much work. This toolkit is designed for the work to happen in the meetings. The toolkit is very light on work assignments outside of meetings. There are only two "homework" assignments and they are simple enough that one person can do them. Further, these assignments (gathering particular kinds of information) are open-ended, so that the process can continue even if some of the information called for is scant or not easily available.

The format for each meeting is laid out in the toolkit, complete with basic descriptions, time requirements, to-do lists, and outcomes. The assessment and plan itself make up a working document that is filled out progressively during each meeting. This allows team members to see progress. The end result is not a pile of notes that need to be turned into a report. Instead, the team has a working document with background information, goals and measurable outcomes.

Finally, the toolkit's design acknowledges that different people work in very different ways. Getting a group of people to work well together is at least half the battle in community development. CAPT takes this into consideration. Some of the early meetings, for example, simply gather information about the community and services available. This is because the process of gathering and then talking about the information is just as important as the information itself. The meetings have been carefully structured to help develop a solid, cohesive team atmosphere for the harder work in the middle and at the end of the process.

Getting Started

Welcome to the Texas Community Assessment and Planning Toolkit. This resource was developed to help community leaders assess and, where necessary, plan to improve the way communities welcome people with autism and other disabilities, as well as identify how they contribute to their communities.

The toolkit is based on the accumulated knowledge of experts in the fields of disabilities and community development, such as John McKnight and Peter Block. It will help committed community leaders – Champions – rally local support and change how their community views and includes its members who are living with a disabilities(see Inset: The Role of the Champion). Although developed specifically with autism spectrum disorders in mind, the principles and methods presented here apply to all those who struggle to access their communities because of a disability.

The work begins with gathering a task force of community members and leaders. This process should take no more than six meeting in six months. All work, with some minor exceptions, takes place in the meetings because a process laden with "homework" for a group of business and community leaders will end up struggling with delays and decreasing investment. For the same reason, the process is also designed to take advantage of information that can be gathered easily, rather than requiring extensive time and resources to seek out hard-to-obtain data.

The Role of the Champion

The idea of a Champion is taken from the business sector. Research on successful corporate product development and quality improvement reveals that an internal Champion, a senior manager or an executive who sincerely supports the product or proposed change, is critical to success.

In this context, the Champion is a community member or leader who wants to create significant change. It may be the person who sought out this kit or who opened the box and started the process. This person may be an agency leader, a parent of a child on the spectrum, or someone with autism. He or she will guide the process and keep it on track. If the Champion is not fully invested and committed, the task force (see below) will be a committee that may get some results but that lacks the energy to create sustainable change.

The toolkit is a step-by-step guide to assess and plan, and includes helpful hints to use along the way – lessons learned from real-life planning and policy work. After completing this process, you will have a plan with goals (what), action steps (how), and the outcomes each goal will accomplish (why). There will be outcomes and many completed tasks as a result of your work. Larger outcomes are unique to your community and are the result of successful assessment and planning, such as improved parks for people with disabilities. Tasks and meeting-related outcomes are listed at the end of each meeting description. Use these tasks and outcomes to track your progress. If you are not accomplishing the tasks and outcomes set out in each step, you may need to reconfigure the membership of the group or revisit your mission. The last section of the toolkit consists of a list of suggested readings for those who want to dig deeper into the theory behind community development.

It is also important to understand what this toolkit does not do. It does not replace community roles such as advocacy groups or government-based funders, although these groups may be included (or kept informed) and may benefit from the process (see Inset: Why You Should Not Focus on Funding).

Start by reviewing the whole toolkit, so you can picture the entire process, then jump in! We hope you will find the toolkit helpful and productive. However, it is only a tool. So use it as it works best for your community. Results come from the Champion's commitment and enthusiasm and spreads through the task force to the whole community.

Why You Should Not Focus on Funding

When it comes to funds for services for people with autism or other disabilities, we can be certain of two things: there is not enough of it, and what there is could be better spent. If you start thinking about funding when you create your plan, you will spend all of your time thinking about it, only to arrive at these two certainties. That is not the point of this process. Your plan should address things that are already happening in your community but will not replace them. You are not justifying the need for more funding; government officials and service providers already do that and should continue to do it even when this new plan is in place. This toolkit will help you to develop new networks and resources or connect existing resources in a new way. Start with that, and the funding will follow, because your community will have a better idea of what it wants to buy with the money that is available.

At the same time, however, funding is clearly important. As you look at your community and the array of services available, gaps, duplications and the need to find funding to correct them will become obvious. The point is that funding has its place in the discussion, but it should not dominate or stall the process.

How Do You Find a Champion If One Does Not Spontaneously Appear?

At this point, it may be tempting to fall back on people with certain titles or "expertise." Those people may be important to this process but, as anyone involved with this kind of initiative will tell you, merely having a particular job title does not guarantee passion, commitment or focus. In fact, having a highly demanding job, as many experts do, sometimes makes it harder to maintain sustained effort and drive on a single project.

Instead, here's how to find a Champion. Ask yourselves these questions (not in any particular order):

- Who has the most to gain from this project succeeding?
- Who has the most to lose from this project failing (or never being attempted)?
- Who has been vocal about wanting positive community change?
- Who has a temperament that can maintain positivity, attractiveness (making people want to participate), focus and persistence?
- Who has demonstrated skill for seeing the big picture and keeping things moving?

You may not come up with one single name that incorporates all these qualities but several that fit some or many of these traits. Spend some time coming up with a couple of combinations that you think capture the most important qualities for your project. You may find that a “titled” person or expert has all these traits and may be the right choice after all (but be careful to ensure that such a person can devote the time and energy needed).

And finally, like most things in life, this is not a one-time-only, all-or-nothing effort. You may approach a potential Champion who initially agrees to take on the role, only later to decide that he or she does not have the time to commit to the project after all. Or you might discover that you have a Champion who is not meeting basic tasks and timelines as the project advances, while other committed individuals have since emerged.

It is OK to shift that role if needed, and it is OK, (in fact, it is a great idea) to have more than one person in mind for the role of Champion in case of any unforeseen events. You could also conceivably have more than one Champion at the same time, if a particular pair of people work well together and complement each other’s qualities. In other words, do what fits your situation and what makes sense to you, and don’t hesitate to make adjustments or changes along the way. It’s a process, after all.

Forming the Task Force

Members

The task force is the group of people who will write the plan. They may also gather additional information, but this group’s main responsibility is to complete the assessment and create the plan. The task force should be relatively small, with no more than 10 members, representing a wide range of perspectives, including:

- Someone with autism, including at least one young adult
- A family member
- An expert on autism (e.g., physician, academic therapist)
- A representative from the business community
- A representative from local government (city and/or county)
- A representative from the service provider community
- A representative from a local school district
- A representative of first responders such as the police or fire departments
- A representative from local higher education
- A representative from some other community leadership, such as clergy or a volunteer association

All members except two can assume more than one role; those are the members with autism and the family member may serve in those roles only. When choosing members, think about other aspects of the community you may want represented, such as healthcare and transportation.

Most likely, some of the task force members have already volunteered. Talk to this core group of committed people first to draw on their support and insight to identify other task force members

It is important to remember that the areas represented on the task force do not make up a prescribed list. The group must be tailored to the community. This may take some time and effort, but it is worth the investment. A group of experts assigned to a team to complete a task will do just that – and nothing more. A gathering of invested and committed community members, on the other hand, will create meaningful change (see Inset: A Lesson from the Ohio Interagency Workgroup on Autism).

A Lesson from the Ohio Interagency Workgroup on Autism

In 2008, Ohio's governor asked the Ohio Department of Developmental Disabilities (DODD) to create an interagency workgroup on autism. The department was determined to learn from past successes and failures. Based on experience, DODD decided to form the group slowly, and invited colleagues from other state agencies. Invitations were based on personal commitment and willingness to collaborate, not on official titles or "expertise."

This approach was risky, because it meant that people who knew a lot about autism, funding or policy would not be at the table. However, the gamble paid off. Due to its members' genuine investment and skill at collaborating, the workgroup thrived, producing lasting system improvements for autism even during the worst economic downturn since the Great Depression. The lesson? Pick commitment, not just job descriptions. Expertise is great, but it's better if it comes with commitment.

Invitations

The next step is to approach potential task force members through a personal contact, followed with a formal, written invitation. Make the invitation personal, and include a few key details about the process and timeline. Because it can be difficult to create excitement and establish personal investment in a letter, and this medium is easily refused or ignored, the first contact should be personal, such as through a telephone call or in a brief face-to-face meeting. The information to be covered should be identified and rehearsed ahead of time (see Inset: Elevator Test). In addition to the overall goals of the task force and key information about the process, details such as the time and location of the first meeting should be stated within the invitation.

Overall Considerations for Meetings

The toolkit describes a process comprising six meetings over the course of six months. There are two occasions for which homework is required. These assignments are explained in detail. This process is designed to draw upon existing resources and, as such, participants are positioned naturally to gather this information.

Please give special consideration to the location of your meetings, and choose a facility that is accessible to people with disabilities. Participation in the process will be greatly discouraged if people have to drive too far to the meetings, or they feel uncomfortable in, or unable to access, the meeting space. While this process is probably best experienced in face-to-face meetings, teleconferencing can be used if task force members can't physically be present.

Hosting a successful meeting is an art, and nothing teaches better than experience. Many tactics support forward movement and provide some fallback options if progress stalls (see Inset: 12

Helpful Hints). However, passion and commitment have their own sustaining power, so rely on them, too, to keep the task force's progress on track.

Remember…

All communities are unique, and have different resources and supports available. Creativity is key when it comes to gaining resources and support. It helps to think about what already exists in your community that can be used to further your goals. Are there businesses in your community that would donate money to your task force for snacks or supplies? Is there a school or a church that would donate space for your group to use?

Elevator Test

Imagine that you want to ask an important person to support the project, but you know he or she is very busy. You have almost given up on the idea of involving the person when you accidentally bump into him or her in an elevator. Given this opportunity, can you sum up the entire venture, create excitement, and end with an invitation – all in the 30 seconds of this elevator ride?

This is the elevator test. Your idea of what you want to accomplish should be so clear and so focused that you could convey your vision in a few simple sentences. Rehearse this speech. This will not only help you take advantage of these kinds of chance encounters, but more important, it will help you and the task force to stay focused on your goals.

How to Host Successful Meetings: 12 Helpful Hints

1. Have flip charts or whiteboards and markers ready, even if you don't anticipate using them. If you don't have them handy, you will invariably wish you did. You may also want to have a ready supply of sticky notes, paper and pens handy.

2. Begin (even if everyone has not arrived yet) and end meetings on time. This is respectful of members' time and creates a sense of urgency. If possible, end a bit early to allow for a relaxed chat time after the "official" agenda.

3. Once the schedule is set, do not cancel or postpone the meeting. Trust that those who should be there will be there.

4. Don't sweat details. Details feed the concept but are often forgotten. The concept creates change. Agree to disagree, or to come back to a small point later.

5. Feed everybody, but be particular about what is served. No sugar! (More on this later.)

6. Hold the meeting in a comfortable room with space to walk around. This will allow people to sit, stand or walk as they participate. This creates a working, yet open, environment. It is important that members stay in the room for all discussion so that participants can hear everyone else's views.

7. Before the meeting, do something to change the setting. Arrange the chairs more casually or adjust the lighting. This demonstrates that you are gathering to do something new.

8. Have stress balls or other small objects available. These help some people to relax and think creatively.

9. Use name tents, not nametags. Adhesive nametags can be unfriendly to certain fabrics and catch long hair.
10. Don't assign note taking to a task force member. Arrange for a competent assistant to do that. This allows all members to think about the task at hand, not recording it. It is worth the expense.
11. Record all ideas and do not push for consensus. The goal is new ideas, not a unanimous vote.
12. Use a "parking lot" – a whiteboard or large piece of paper – where people can record ideas that are not immediately relevant but have potential or need further discussion. However, make sure to come back to them!

Meeting 1

The foundation of the process is laid during the first meeting. Its primary purpose is to establish direction for the task force and create understanding of the assessment and planning process. The meeting will take about two hours. It is important to remember that the group is newly formed and that many members may be meeting one another for the first time. Keep in mind, however, that this is a task force that is gathering to accomplish a specific task – not an ongoing team. So, while it is important that everyone knows each other's names, do not spend time on team-building exercises, which are designed to jump-start working relationships. These relationships will occur naturally within the scope of the work.

Remember that the task(s) that the group wishes to accomplish are challenging. Making decisions is tiring. The more participants care about the outcome, the more tiring it is. If you enjoy the process, it is less tiring, but only to a point. Keep this in mind for the part of the meetings where people have to make decisions. Some of the difficulty comes from having to choose one thing and reject another. Choosing one option means dismissing others. Some people find this so stressful that they become exhausted and impatient, and when people are exhausted and impatient, they make bad decisions. Other people may want to avoid that stress altogether and suggest "tabling" the decision; as a result, a decision never gets made. It helps to take good notes so that some ideas can be set aside and kept for later, if needed. Keeping a record of all ideas presented also helps to validate and document task force members' contributions to a discussion.

Too many options can make decision-making difficult. Have the group quickly select their top three choices, and base the decision on those. Limit the time allotted for choosing a topic. (Remember: Good notes can save ideas for the record, if people are worried about them being forgotten!) Start with easier decisions first. Do not use up reserves of time and energy, or risk frustrating task force members, by trying to answer the most difficult questions early on.

Refueling the Brain

Remember that making decisions requires mental energy, and that means your brain needs fuel. Refuel, refuel, refuel! Doughnuts, cookies or fruit are often provided at work gatherings, but this is not a good idea. Instead, make available protein and whole grains, rather than pastry, chips, candy, fruit or sugary drinks, throughout the meeting. Whole-grain bagels and cream cheese, for example, provide gradual, long-lasting increases in blood sugar, which is the energy our bodies need. Sugary foods create a quick spike in energy, but this rush is followed by an equally fast drop. You'll see people nod off or lose their concentration when their blood sugar drops, so "slow and steady" is the idea here.

Also, hold meetings early rather than late in the day, or consider special Saturday morning sessions. This will help ensure that people are not overly tired or stressed when sitting down to do this work together.

Tasks for the First Meeting

- Introduce members and gather email contact information.
- Introduce the toolkit and the process you will be following.
    - Hand out a blank copy of the worksheets or other relevant pages from the toolkit so team members can prepare for discussion.
    - Schedule the next five meetings.
- Discuss guiding questions (see Inset: How to Use the Guiding Questions and Derived Consensus).
    - What do we "know" about people with autism and other disabilities?
    - Are there things we don't know, or things that might be based on inaccurate information?
    - Do we have any doubts about our ability to fully integrate people with disabilities into our community?
- Assign homework (see Inset: Homework: Profile of Your Community).
    - Gather community and demographic information about your community
    - Follow Section Two on page 13 as a guide

Derived Consensus

In derived consensus, everyone proceeds with basic agreement on large-scale principles. With specific consensus, on the other hand, everyone comes to formal agreement. Derived consensus is a "sort of unanimous" agreement on a concept that is not yet fully defined. This agreement may be articulated or derived by the Champion after discussion with the members. Disagreements can be addressed later. Over time, disagreements or points not addressed may evolve into agreement, or a more specific expression can take into account these differences of opinion without holding up the overall process.

Outcomes of the First Meeting

- Completed Section 1 form, page 10
- Assigned homework for one or two task force members
- Established dates and secured locations of the remaining meetings and communicated this to the members

Section 1: The Task Force

The Champion	
The Recorder	

The Task Force

Name	Phone	Email

Summary of Meetings

Meeting	Content	When	Where
Meeting 1	Getting ready		
Meeting 2	Our community		
Meeting 3	Services		

Meeting 4	Six Conversations		
Meeting 5	Planning		
Meeting 6	Wrapping up		

Summary of Guiding Questions

- What do we "know" about people with autism and other disabilities?
    - *This could be family members or friends. Some task force members may not know anyone with autism.*
- Are there things we don't know, or do we have information that might be based on inaccurate data?
    - *This is an opportunity to explore misconceptions about autism and other disabilities, and the people who struggle with them.*
- Do we have any doubts about our ability to fully integrate people with disabilities into our community?
    - *This question allows the group to further explore presuppositions. (e.g., Can people with disabilities be productive employees?*

Homework: Profile of Your Community

This assignment is to gather information about your community for discussion in the second meeting. For many communities, the source of this information is the Chamber of Commerce. Go there first, because they probably have done the work for you or can help you gather it very quickly. Many chambers have community profiles summarizing everything that the task force needs. Chambers routinely collect information on…

- Demographics
- Education
- Arts, culture and entertainment
- Transportation
- Healthcare

How to Use the Guiding Questions

Each meeting outline includes guiding questions taken specifically from the toolkit. These questions establish a focus for the discussion and move members toward the goal of the meeting. Hopefully, the discussion will flow freely, so you may not need to specifically ask the questions in the meeting. The note-taker must take care to record the discussion thoroughly, because the answers will be summarized for the plan.

Do not push the group to reach a traditional consensus in this discussion. Rather, allow for derived consensus. Using this method, the themes of the discussion are identified and reported at the following meeting for all to quickly review and accept. With derived consensus, the Champion takes responsibility for summarizing the overall themes of the discussion and avoids wrangling over details or falling into the wordsmithing trap.

Chamber websites typically offer a variety of reports and can connect you easily to data from other sites. Another good source is http://quickfacts.census.gov. For more detailed information on your community, you may also consult your education service center or local school district.

Another helpful place to look is City Hall. In addition, larger cities' websites usually include neighborhood-specific information. Portions of this work may have been done to recruit larger businesses. Therefore, the representative from the business sector on your team may be best suited for this assignment.

Remember: For this task, access and take advantage of work already done – don't reinvent the wheel. The research is meant to be helpful, not exhaustive, so don't overdo it. The purpose is to identify information that provides a well-rounded portrait of the community to identify strengths. Incidentally, this is the same type of information that politicians and business people are interested in sharing with community members.

Meeting 2

The purpose of the second meeting is to develop a picture of the strengths of the community. This meeting will take two hours. Start with a presentation of the community information gathered after Meeting 1 (the homework assignment). This should take no more than 30 minutes. The guiding questions identified during the first meeting will help shape this information into a few key strengths and allow a focus on the primary conversation: How can the community fully involve its members with autism and other disabilities? To some, this stage of the process may seem to be off-topic. However, it is a necessary step, and the work completed here will pay off in the end.

As you think about your community, some specific and obvious facts may pop out of the discussion. For example, it may be readily obvious that your community needs more public parks, or that it would be helpful if some of the public spaces were fenced in to make it easier for a mother watching her three children, one of whom has autism, play. Such specific needs that present themselves very clearly become the first set of goals in your plan. Make sure you get them down. You can refine and prioritize later. For now the important thing is to capture them.

Tasks for the Second Meeting

- In five minutes or less, summarize the first meeting. Hand out the worksheet with Section 1 completed.
- Ask the members who gathered the community information to summarize it. Again, set a time limit.
    - Discuss guiding questions.
        - Having reviewed the information presented, do we feel generally positive or generally negative about the community?
        - Think about the "story" the community is telling. Is it a quiet and soothing story, action-packed and exciting, or something else?
        - Think about "what we have" and "what we would like." Are the two linked? If not, how can we help to link them?
- Assign homework (see Inset: Homework: Profile of Available Services).
    - Compile information about the community, including demographics.
    - Follow Section 3 of the toolkit as a guide (see Inset: Good 'nough).

Outcomes of the Second Meeting

- Completed Section 2
- Assigned homework to the provider and government representative of the task force

Section 2: Our Community Profile

A community is not necessarily the same as a town or city. Sometimes a community is a neighborhood or a section of a town. In some cases, a community is a township that includes large rural areas. This first section gathers basic information about your community and will help you think about how members of your community navigate it – both geographically and socially. The information you gathered from your Chamber of Commerce or business leaders should be summarized here and recorded for reference. The idea is to get a bird's-eye view of your community and a general idea of what assets your community has.

To put the task force members in the right frame of mind for this discussion, ask them to think about their own experiences in the community. Ask about the three ways we all engage in community: Firstly, do I have places to shop and buy things I need? Secondly, are there places for me to work so that I might make a living or at least some extra money? And lastly, are there activities for me to participate in for fun or learning?

This is important because you have to look at your community from as open a perspective as possible. Two distinct ways of thinking must emerge from this assessment. You should have a general perspective of your community from the viewpoint of an individual without ASD, and you must also have an understanding of how people with ASD perceive the community. For instance, from one angle you may conclude that your community has a strong youth athletic organization. However, you might then look at that organization from the perspective of someone with ASD: "Is it accessible? Are there things that meet my interests and abilities? Is there someone to talk to who can help me find those activities?" Standing in their shoes, your community may seem to lack athletic opportunities completely. Seeing community assets from both perspectives takes time and thought, but it is necessary to get a complete

Good 'nough

An expert in person-centered planning for people with disabilities once remarked that she wanted to have a tattoo on her hand saying "Good 'nough" to remind herself not to get bogged down with too many issues. Don't let perfect be the enemy of good. When you gather and review information of services available for people with autism in your community, it is easy to get carried away in the details. For example, certain members of the task force may tell you that "speech-language therapy is an important service for people with autism and there does not seem to be enough therapists around." This opens all sorts of important questions, such as: Just how important? How many speech therapists are there in town? What are the major funding sources for speech-language services? Faced with these kinds of questions, the group can get lost quickly.

It is important for the task force to get a general picture of services available – enough to identify gaps in services. At this point, it is not necessary to produce an exhaustive report of services. That may be necessary eventually, but that is not the job of this task force. Look at it this way: If there is a shortage of speech-language therapists, for example, the task force may be in a position to inform policy makers through the government and provider representatives, but the manager of the grocery store, sitting on the task force, cannot provide speech therapy. She can, however, let the provider in the group train her staff on how to recognize and respond to a customer who has problems communicating. That is the practical, win-win solution you are after in this work: The person with a disability gets to shop more convenientl, and the grocery store gains a loyal customer.

and accurate picture. Giving extra weight to the voices of team members with ASD or to their family members is a good way to do that.

Helpful Hints for Developing Your Community Profile

Remember, don't worry about details. What you need here is a general view of your community. For example, knowing that your community has some apartments is important, while knowing exactly how many vacancies you have right now is not.

Use the worksheet to guide your discussion and to help sift through the information you gathered from the homework.

Think about transportation. Communities are unique in this area so, as you discuss community assets, remember to consider how far people may have to travel to use them. This will help you think about needs in a different way.

Provide two answers to each question: One from the standpoint of a person without ASD and the other from the perspective of someone with ASD. Discuss the differences that emerge.

Community Profile
Describe your community. Is it a small town or a suburb; an urban neighborhood or a rural township?
What is the population of your community? (You may need to estimate here, and that's fine.)
Is your community ethnically diverse? Multilingual? (This is important to get to eventually as you think about the things you plan to do as a result of this work. For example, if you print resources, you may need to think about translations. For now, though, it's most important that you have an overall sense of your community that you all agree on.)

Residential/housing. Describe the housing available in your community. Do you have a variety of housing (houses, apartments, etc.)? Does your community have low-income housing? How does your community deal with homelessness?

Business. Does your community have a thriving business sector or is it struggling? What is the unemployment rate for your county? Does your community have a variety of jobs, like manufacturing, or are there mostly service jobs -- for instance, in hotels or restaurants? Remember, people with autism and other disabilities often have difficulties with transportation, so think about the job situation in your community, not in outlying areas that may be difficult to get to.

Arts/entertainment. What kinds of outlets for arts and entertainment does your community have? Do you have a community arts center? Does your community have restaurants or movie theaters? Can you identify where young people hang out?

Social/recreational. Does your community have recreational resources that are free or low-cost, such as a YMCA? Are there outdoor athletic venues such as basketball and tennis courts, a public pool, or a skate park? Does your community have indoor options, such as a bowling alley or a video arcade? Does your community have organized athletic associations for children and adults? Does your community have an active Special Olympics chapter?

Cultural/religious. Does your community have a variety of houses of worship? Are theyactive in your community (i.e., sponsor or participate in civic events)?

Education. Do the schools in your community offer extracurricular activities? Do the high schools in your community offer vocational and jobs training programs? What about higher education? Do you have a community college or a four-year institution in or close to your community?

Medical care. Does your community have doctors or clinics that serve your community or do you have to go elsewhere for health care? Do you have a hospital nearby? Does your community have specialists, such as psychiatrists, nearby? Do you have physical therapy or speech-language therapy nearby or do you have to go elsewhere?

Summary of Guiding Questions

These discussion questions may seem general and off-topic. Trust the process, and remember that a community that is good for people with disabilities is a community that is good for all its members.

- Having reviewed the information presented, do we feel generally positive or generally negative about the community?
    - *Do you think your community is a well-rounded, good place to live? If so, why? If not, how could it be better?*
- Think about "what we have" and "what we would like." Are they linked? If not, how can we help to link them?

Homework: Profile of Available Services

This assignment calls upon the experts to be experts. First, you are asking the provider and government representative to report on services available in your community for people with autism. This report can be informal and will include some services, such as Medicaid or occupational therapy, that are available and applicable to a wide range of people,, and some that are geared more specifically to those with autism. Secondly, you want these representatives to report on emerging trends in the community with regard to autism and related disabilities.

To help in this work, refer your experts to the list of service categories beginning on page 21. This list of categories was developed at the Ohio Center for Autism and Low Incidence (OCALI) with assistance from researchers at Harvard University and Ohio State University. It provides a well-rounded picture of services without making any judgment calls or value decisions.

Through this process, the task force draws upon the special knowledge of the experts in the room – the provider representative, the government representative and, when available, the representative from higher education. Take advantage of the task force's expertise.

Here are two helpful hints to think about:

1. Talk to the provider and government representative about this work at the beginning of the process so they have time to assimilate a vast amount of information and condense it into a useful form. It might be good for the Champion to meet with them outside of meetings so they can define what this report will encompass.

2. Ask the experts on the task force to review existing reports or databases. Enough of this information to meet your needs may already exist in one place. The resources mentioned for the first homework assignment may be helpful for this task as well. If not, you now have a recommendation for your government representative.

Meeting 3

The third meeting is dedicated to understanding the array of services and supports available to people with autism and other disabilities. This meeting will take two hours. Start with a presentation of the services available as determined in the homework after the second meeting. This should take no more than 30 minutes. The guiding questions will help condense this information to a few key points and encourage a conversation focused on those points.

As with Meeting 2, you may think of things that are specific and obvious facts. For example, one of your members might report that she is aware of a shortage of a certain kind of service that your community needs. Again, the specific needs that present themselves so clearly become the first set of goals in your plan. Make sure you get them down for refining and prioritizing later.

Tasks for the Third Meeting

- Quickly, in five minutes or less, summarize the second meeting. Hand out the worksheet with Section 2 completed.
- Ask the members who gathered the information on available services to summarize it. Again, set a time limit.
- Discuss guiding questions.
  - Do we hear stories of people with autism going without services?
  - Does our community have a wide range of services available for people with autism?
  - Think about "what we have" and "what we would like." Are they linked? If not, how can we help to link them?

Outcomes of the Third Meeting

- Completed Section 3

Section 3: Assessment of Services

The third section looks at the services and supports available to people with autism and other disabilities in your community. It is important to remember that your objective is to gather enough information to keep up the momentum to move to the next level. Don't let perfect be the enemy of good! As you review the information, keep in mind that you need to balance facts with perception. For example, some providers may say that they have plenty of openings for a given service and yet families say they can't find that service anywhere. Both may be true. If, after you gather even basic information, you can't figure out what services are available, image how difficult it must be for families. They're at the table, so ask them.

If it proves too difficult to get even the basic information you need, ask the government representative on the task force to get the data outside the meeting. Ask the representative to develop a simple guide to services. She is in a position to do this; the task force is not.

We have included a list of service categories developed at the Ohio Center for Autism and Low Incidence (OCALI) with assistance from researchers at Harvard University and Ohio State University. The categories were created for a survey of families. Because the survey was to assess which service families knew about and used, the categories were not limited to evidence-based services. Many of the categories listed are evidence-based, but they may not have evidence-based application to autism. Since many families use them, they are included here.

Should We Be Concerned With Evidence-based Practices?

Yes! A practice is evidence-based because we have ample research evidence that it works. Two of the best resources for evidence-based practices in autism are the Texas Autism Resource Guide for Effective Teaching (TARGET) and the Autism Internet Modules (see Resources for URL).Evidence-based practices are valuable, but they are not everything. Remember, there was a time when every evidence-based practice was just an idea and research had not yet fully tested it. So while it is necessary to be concerned that evidence-based practices are available, we must be open to emerging and promising practices – interventions that appear to work well even though additional research is still needed.

This is important for a number of reasons. First, the pool of evidence-based practices changes with additional research. Additionally, innovations in related fields may provide critical new insights. Also, it's rare that a single practice covers all the bases. With autism, this is particularly true. Though a condition that most noticeably affects the brain, autism is a whole-body condition, affecting a person psychologically, physically and socially.

Assessment

In assessing the services available in your community (Section 3), keep an open mind. This section is broken up into categories of services. It is not a list of endorsed services. Rather, it is more like a net, designed to catch a wide range of services along the continua of

- Approach
- Targeted age
- Discipline
- Dominant need area

This net will help you to catch the variety of autism services that may be used by families in your community. It may also help you identify significant service gaps when you begin planning. Don't worry about evaluating the approaches. Your task force will likely not have the time or scope to decide which autism interventions should be used by families in their particular situations. Instead, you are developing an inventory of what is available. If the community decides other supports or services should be made available, that can be part of your plan, or not, as you see fit.

Planning

When you get to the planning section, knowledge of evidence-based practices will be helpful. You want a rich mixture of evidence-based, consensus-based and emerging practices in your community. It has been said that if we had stressed evidence-based practice in the 1940s as much as we do now, we would have sleek, compact iron lungs but no polio vaccine.

Helpful Hints in Developing Your Community's Service Profile

- Remember, don't worry about details. What you need here is a general, bird's-eye view of services. If you find this task difficult, that difficulty may be the most important information you will get from this section.
- Use the toolkit to guide your discussion and to help sift through the information you have from the homework.

Again, think about transportation. Ask, does the service come to me? If not, how do I get there? This will help you think about capacity in a different way.

Assessment of Services Sample Form

The form for Meeting 3 is only a list of services that might be available in the community. It is not an evaluation or endorsement of these services. Some of these services may be evidenced based; others may not be.

EXAMPLE: Naturalistic play-based or developmental relationship-based interventions

These services primarily take place in natural settings, fit into everyday routines, and have a strong focus on social interaction and building relationships.

Examples include …

- P.L.A.Y. Project (Play and Language for Autistic Youngsters)
- DIR Models (Floortime) (Developmental, Individual Difference, Relationship-based Model)
- Responsive Teaching
- RDI (Relationship Development Intervention)
- SCERTS (Social Communication, Emotional Regulation, Transactional Support)

Does your community have these types of services?

No	[✓ **Yes, very little**]	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

We were not completely sure what this was, but one of our members knows a family who connected with a P.L.A.Y.-certified provider for her 2-year-old after she and her pediatrician noticed some delays. She swears by it.

There doesn't seem to be any other providers of this kind of service in our community. All agreed that we should look into this further, especially for very young children. Sara volunteered to do a little research and email the results to task force members.

Behavioral Interventions

These interventions can be moderate to intensive and range anywhere from a few to 40 hours a week. They are designed to increase functional behavior and decrease maladaptive or undesirable behavior.

Examples include …

- Modifying the environment
- Applied behavior analysis such as discrete trial training
- Pivotal response training
- Incidental teaching
- Specific instruction

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don't know

Discussion

Integrated Physical Medicine

These are physician-based medical interventions that take a whole-body approach.

Examples include …

- Chiropractic medicine
- Osteopathic medicine
- Cranial sacral therapy
- Massage

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don't know

Discussion

Biomedical interventions

This includes other medically oriented alternative approaches.

Examples include …

- Special diets (such as gluten- and/or casein-free)
- Use of specific vitamins and/or supplements

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

Additional therapies

These are license- or certification-based therapies not specific to autism but considered by many to be very helpful.

Examples include …

- Speech-language therapy
- Occupational therapy
- Physical therapy
- Music therapy
- Art therapy
- Sensory therapy

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

Alternative therapies

These are additional established therapeutic interventions, not specific to autism but considered by some to be helpful.

Examples include …

- Therapy with animals (horses, dogs, etc.)
- Aquatic therapy
- Acupuncture
- Other alternative therapy

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don't know

Discussion

Assistive technology

This includes any adaptive equipment or use of technology that research has found to be helpful or is just beginning to explore.

Examples include …

- Adaptive equipment
- Specific instructional materials
- Assistive technology devices
- Computer
- Communication device
- Touch screen
- Picture communication systems

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes**	**Don't know**

Discussion

Summary of Guiding Questions

- Do we hear stories of people with autism going without services?
- Does our community have a wide range of services available for people with autism?
- Think about "what we have" and "what we would like." Are they linked? If not, how can we help to link them?

Meeting 4

In the fourth meeting, the task force will go through the Six Conversations (see Section 4). This meeting is more reflective than task-oriented. It will take three hours and will require a flip chart. The meeting begins with a quick summary of the process work done to-date. This update should be very brief, not only because the task force needs the time for other work but because the content of this meeting requires a fresh perspective. Reminding the task force of the progress is important, but a lengthy discussion should be avoided.

The information generated by the task force over the past three meetings has been condensed to fairly concise answers to the guiding questions on the template. All input and notes from the discussions that do not appear on the worksheets now come into play. There are three categories of information:

- **Notes from other meetings.** This includes the relatively disorganized notes, drawings, and observations written on flip charts and dry-erase boards recorded from the meetings. It also includes any other notes taken at the first three meetings.
- **Completed worksheets.** This is the concise information gathered so far.
- **Task force members' general thoughts.** This last category consists of the thoughts and perceptions of the group members. Although you don't know exactly what everyone is thinking, it is important to remember that each member has reflected on the work in different ways.

Now it is time to begin assimilating these ideas and information. The Six Conversations will help you.

The following diagram will help the group articulate the community's past as well as its future.

What makes your community great? What could make it better?

Do the services that are available truly support people with autism and other disabilities to be a part of their community?

How can people with autism and other disabilities fully participate in the community so that the community benefits from them?

What can the community do to make things better for people with autism and other disabilities?

The fourth meeting is primarily open discussion. Therefore, the guiding questions for this meeting do not appear in the template. They are designed to allow the vision of the group to come together. The task force has accomplished two things so far: It has educated itself on the strengths of the community and the relative status of services available to its members with autism, and it has created a common ground for planning.

The next step is to brainstorm possibilities. From one perspective, this is the fourth meeting in a process of six meetings. From another perspective, this is a starting point – a time when task force members ask themselves two questions:

1. Now that we are all on the same page, how can our community respond to people with autism so that they can fully participate in the community?

2. How can the community welcome their contributions?

Tasks for the Fourth Meeting

- Quickly, in five minutes or less, summarize the whole process to date.
- Discuss guiding questions.
    - Six Conversations: In this meeting, the group will engage in six "conversations." Each conversation asks questions, and the participants write down the conclusions reached in each conversation. Each conversation should be limited to approximately 20 minutes. The results of this meeting may feel open-ended and vague but don't worry about that. It is intentional. Participants will use this foundational information to guide the development of plans.

The Six Conversations

This process, squeezed into one three-hour meeting, is an abbreviated form of a process developed by Peter Block (see Readings), noted consultant and community builder. He built this work on research about how groups and communities structure themselves. Block's Six Conversations come from first-hand observations of what happens when real possibility and community strength are paired with commitment and belonging.

This abridged application does not replace fully engaging in the Six Conversations in community building. After completing this process, your task force should consider hosting larger community "conversations." However, the abridged version does create a unified vision of what a community can do together. Block's methods have been used successfully in the Positive Culture Initiative, sponsored by the Ohio Department of Developmental Disabilities. This policy initiative resulted in positive behavioral guidelines and the banning of prone restraint in Ohio in 2009.

Conversation 1: The Invitation

The first conversation is an invitation. In your planning process, the "invitation" conversation actually began in the first meeting. As you are reading this now, the task force has a bit of history behind it, and working relationships have emerged. Yet, it is a good idea to start this fourth meeting with a welcoming invitation. You might ask how the group is doing and encourage honest answers. Although it may feel unnecessary at first, this is a good opportunity to revisit the point of the project – to welcome people with autism into the community – and to reinforce how recognized and valued we feel when we are genuinely and explicitly invited to be a part of something. A brief reflection on this may help renew enthusiasm and empathy in the task force's work.

Conversation 2: Possibilities

The conversation about possibilities has to be exactly, and only, that – about possibilities. We usually solve problems by defining the problem, setting goals, and implementing solutions. In the possibilities conversation, the role of the Champion is to guard against the group's tendency to problem-solve and to encourage members to stick to possibilities. Instead of asking, "Where do we want to be in a year or two?" and then immediately jumping to the question of how to get there, ask, "What does our community look like in a year?" By asking how it looks, it is easier to keep the group focused on the possible future as opposed to barriers today. In this conversation, take a few minutes to allow members to grasp the transforming power of declared possibility.

Change may start with an individual's dream. But possibilities are not dreams, and community possibility is not a gathering of individual possibilities. This is a difficult concept to grasp. You are asking people to go against the grain. In a sense, you are asking task force members, "How do we know we've done a great job?" when they don't even know what the job is yet. Trust the process, and trust the group to tolerate this confusion until the process unfolds completely.

- **Guiding Questions** (Have paper available so the group can write or draw the answers)
  - For you as an individual, what does our community look like when we are finished? In a year?
  - What do we want to create together that will make a difference?
  - What can we create together that we cannot create alone?

Conversation 3: Ownership

Peter Block says, "Community will be created the moment we decide to act as creators of what it can become. This is the stance of ownership, which is available to us every moment on every issue …"1 Start by asking the group the tough question: What have I done to contribute to the very thing I complain about or want to change? The power of this question comes from following the conversation about possibilities and ends with a declaration: We are ready to create what our community is to become.

- **Guiding Questions**
  - How valuable do you plan this project to be?
  - To what extent are you invested in the well-being of the whole community?

Conversation 4: Dissent

Dissent is not only necessary but also ever-present, whether you are aware of it or not. Supreme Court decisions often contain a dissenting opinion. Even when a different decision is made, dissent is important, and the court acknowledges that by publishing the dissenting opinion. The same approach and attitude apply to a community-based assessment and planning effort. Dissent essentially creates diversity, and welcoming dissent is to welcome different ideas and perspectives. In other words, this fourth conversation creates space for the "yes, but" that inevitably surfaces in this process. Your best bet is to call it out and welcome it.

- **Guiding Questions**
  - What lingering or emerging doubts do you have?
  - Have you said yes to something you don't really support?
  - What differences do we have among us about this project?

Conversation 5: Commitment

This conversation might be called "beginning to commit." Based on the previous conversations, especially the conversation of dissent, the group uses this time to begin forming a commitment. There is a difference between commitment to do something and commitment to a plan. If you commit to do something and the plan you have for doing it fails or falters, you keep going. This is the level of commitment we are seeking here. This is a profound step, so allow it to emerge gradually in this conversation. A more mature commitment and dedication to a specific plan will come in the fifth and sixth meetings

- **Guiding Questions**
  - What commitment are you willing to make?
  - Are you ready to risk failure and start again?
  - Are you ready to risk success?
  - What story about your community do most identify with?
  - Are you ready for that story to change?

Conversation 6: Gifts

This conversation comes last because it is the most important and the most difficult. "Gifts" in this context means things that you bring to the table – a contribution, a strength, an asset. It is ingrained in us to seek weakness and eliminate it. Merely eliminating the bad can work, but it keeps us thinking about the bad, and in some ways ties us to it and to the past. Emphasizing the good creates new possibilities for the future. Changing community is about seeking, supporting and accepting gifts, not focusing exclusively on problems. This requires a fundamental shift of feeling and belief in key community members and leaders.

In this conversation, the process starts with the group itself. The plan you decide on now brings change in thinking and acting. At its best, this can lead to change for everyone in the community as the group moves forward with its plan. During this conversation, stay focused on the task force members themselves and the gifts they bring. Remember, in small groups, belief comes before action, but in large groups – your community – action brings belief over time. Your philosophy about your own gifts will be translated later in the process as you look to the gifts in your community.

- **Guiding Questions**
  - What gifts have you received (personally or for this process) from members of this task force?
  - What gifts have you given in return?
  - How can you focus on gifts and abilities in your work? In your life?
  - Would you rather be known by the gifts you present, your abilities, or by the problems and inconveniences you cause?

Conclusion

Focusing on gifts, on the positive, is the most important thing before you. This is not a task, but a way of being with one other. It is community. From one perspective, this whole planning process has aimed to bring this small group of community members to this realization. Our communities are richer if we learn to appreciate the gifts we offer each other. This is true whether you are trying to make things better for people with autism or trying to eliminate gang violence, increase literacy, or respond to a natural disaster. Commitment, openness, and acceptance of our gifts, these are the leverage points. If you get everything else "right" but you don't get these, you will repeat the past and the present. But if you embrace these stances and the rest gets muddled, even then, you will move into a new future.

Outcomes of the Fourth Meeting

- Notes on flip chart paper for each of the "conversations" above (except for the invitation). These flip chart pages are needed for the next meeting
- Completed Section 4

Section 4: The Six Conversations

Conversation 1: The Invitation

A Brief Explanation

The first conversation is an invitation. In your planning process, the "invitation" conversation began in the first meeting. As you read this now, the task force has a bit of history behind it, and working relationships have emerged. Still, it is a good idea to start this meeting with a welcoming invitation. You might ask how the group is doing, encouraging honest answers. There is no need to document the answers unless you want to. Although it may feel unnecessary at first, this is a good opportunity to revisit the point of the project – to welcome people with autism into the community – and to reinforce how recognized and valued we all feel when we are genuinely and explicitly invited to be a part of something. Reflection on this may help renew enthusiasm and empathy in the task force's work.

Conversation 2: Possibilities

- For you as an individual, what does our community look like when we are finished? In a year?
- What do we want to create together that will make a difference?
- What can we create together that we cannot create alone?

Conversation 3: Ownership

- How valuable do you plan for this project to be?
- To what extent are you invested in the well-being of the whole community?

Conversation 4: Dissent

- What lingering or emerging doubts do you have?
- Have you said yes to something you don't really support?
- What differences do we have among us about this project?

Conversation 5: Commitment

- What commitment are you willing to make?
- Are you ready to risk failure and start again?
- Are you ready to risk success?
  - What story about your community do you most identify with?
  - Are you ready for that story to change?

Conversation 6: Gifts

- What gifts have you received (personally or for this process) from members of this task force?
- What gifts have you given in return?
- How can you focus on gifts and abilities in your work? In your life?
- Would you rather be known by the gifts you present, your abilities, or by the problems and inconveniences you cause?

Meeting 5

The fifth meeting begins to wrap things up. This meeting will take two hours. Remember to post the charts developed in the Six Conversations of Meeting 4. This meeting has a very tight timeline, so be sure to keep things moving. The meeting begins with an open exchange of reflections on the Six Conversations.

When a transition feels natural, turn the conversation to the following concepts:

- Activities of community life
- Dimensions of community life

Activities of Community Life

The activities of community life are the three basic ways in which we interact with others. As community members, we assume these roles:

1. **Earning.** This is the role of the employee. This is the initiating side of any exchange, such as serving customers at a restaurant. It is the first half of the commercial exchange. It is the activity of serving others, an important aspect of community. Just as important, however, it includes economic access. That is, I can be a customer only if I can also be an employee. If I can't fulfill my role as employee, my role as customer is severely limited because I don't have any money.
2. **Buying.** This is the role of the customer. Whether we are going to a movie or buying food, we do so as customers and, in return, we receive something. This role is the receiving end of any exchange and the other side of the commercial exchange. As such, it mirrors the "earning" activity. It also completes the cycle of economic participation.
3. **Participating.** This is the role of the participant. Along with the obvious overlaps with the first two roles, this role also encompasses social/recreational life. For example, do I participate in book clubs, sports leagues, and religious groups?

Dimensions of Community Life

There are three general dimensions to community life, which interact with the activities of community life:

1. **Access, getting in or to.** Community life requires access. This dimension encompasses everything from being able to physically get some place to being welcomed once there. Access is by far the greatest problem for people with disabilities around the world. People with disabilities struggle with access to jobs, services, products, entertainment, medical care and social relationships.

2. **Communication, interacting with others.** Involvement with community requires communication. People with disabilities may struggle with expressing themselves and understanding others, but people on the autism spectrum sometimes have extreme difficulties with communication. As this dimension contains the interactive part of social life, it is very important to consider.
3. **Socialization, being with others.** Very closely related to communication, this dimension contains the informal and nuanced aspects of communication – or being with others. Although this is a general problem for people with disabilities, it can be a monumental problem for people with autism. This aspect includes behaviors that may cause others to shun or distance themselves from an individual.

The task force can now start to pull value statements out of the conversation. Use the community activities grid below to gather group's input. Introduce the example grid first and then the blank grid for participants to work from. Although this may sound counterproductive, don't use the grid as a quiet individual activity. Keep the conversation going while members jot down their ideas and thoughts on their own grids. The Champion can then draw on the conversation and individual input from the collected grids.

	Earner	**Buyer**	**Participant**
Access			
Communication			
Socialization			

Community Activities Grid Example

	Earner	Buyer	Participant
Access	Has a job	Has money to buy coffee	Discovers book club at coffee shop
Communication	Can interact with boss and customers at job	Can order coffee and be understood	Can exchange ideas at the book club
Socialization	Can provide good customer service at work	Can politely point out when coffee order is wrong	Makes friends and does things outside of club meetings

Tasks for the Fifth Meeting

- Quickly, in five minutes or less, summarize the process to date.
- As a group, reflect on the Six Conversations.
    - Now task force members can ask questions designed to elicit very concrete and practical answers. Each member writes down the answers to each question. Responses should reflect what their sector can do and some thoughts about how it can be done. Each member should answer from the perspective of his or her role. For example, the business community representative should answer for the business community, etc.
    - During the remaining time, members report their ideas to the group for discussion. The Champion should be ready to forge connections between the ideas. For example, if the business representative says, “Businesses can train our staff in how to interact with someone with autism,” the Champion can suggest that someone in the provider community might be able to provide that training.

WARNING

Tell everyone to answer in terms of possibilities! DO NOT let obvious barriers such as funding or other resources taint the answers. This is not a time for current reality. This is a time for future possibilities. The work of the plan is to turn current reality into future reality.

- Discuss the guiding questions.
  - Based on the community activities grid, discuss the various activities and dimensions of community life.
    - How can we support people with autism as earners?
    - How can we support people with autism as buyers?
    - How can we support people with autism as participants?

Outcomes of the Fifth Meeting

- Completed Section 5
- List of general goals for the community plan. The Champion's job is to arrange and flesh out the goals as they may need to be pulled from lively conversation
- Before the last meeting, general list of goals in Section 6

Section 5: Activities of Community Life

The fifth meeting is recorded on the community activities grid.

Summary of Guiding Questions

- How can we support people with autism as earners?
- How can we support people with autism as buyers?
- How can we support people with autism as participants?

List any general goals that have emerged from the Six Conversations and the discussion of community life.

Examples:

- Our community has a strong youth sports program. Maybe we can do better and include everyone.

Meeting 6

In the sixth and final meeting, task force members prioritize the goals – both specific and general – develop action steps for each goal, and generate outcome measures for the goals. This meeting will take about two hours.

The Champion prepares a list of specific and general goals following the guidelines for this meeting and records them in the general goal list of Section 6. This meeting completes the process of moving prioritized goals from the general list to the plan itself.

In this meeting, the members review and polish the goals and develop the corresponding action steps. Although this includes some wordsmithing, this activity should be time-limited. While clarity is important, task force members should not be concerned with perfect wording. The final product is the completed template. It is a working tool that can be copied and distributed to the members and to others in the community.

Specific and General Goals

Your final plan will consist of two kinds of goals – specific and general. A specific goal is a goal driven by obvious need, whereas the general goals are driven by a more general view of the future. The interplay between these two types of goals generates a unique blend, and you will begin to see patterns emerging between the two approaches.

- **Specific goals:** In Sections 2 and 3, the task force looked at the community and at services available to people with autism and other disabilities. In those sections, some obvious specific goals were mentioned ("we need more …"; "we have to get …"). In this section of the plan development, you gather, refine and prioritize these goals.
- **General goals:** In Section 4 (The Six Conversations) and in Section 5 (Activities of Community Life), the discussion was more general. Goals that emerge now speak to improving the quality of life of people with autism or other disabilities and their families. It may take further discussion to put these more general goals into words that clearly express what you want to accomplish.

As the task force recalls and records the goals – the specific goals from the second and third meetings and the general goals from the fourth and fifth meetings – you will probably begin to see some interplay among them. For example, from the second and third meetings (assessment), you may note specific goals such as the following:

> "We need more public playgrounds designed to make supervision of children easier, fenced in, far away from busy roads."
>
> "We need occupational therapists serving our community."

Then you note discussions in the fourth and fifth meetings (community life) becoming something more vague:

"We want families with children with autism to find it easier to access public spaces."

"We need a clearer understanding of evidence-based and emerging practices."

When you create the general list of goals, subtle relationships between goals that are clearer (specific) and goals that are more vague (general) will emerge. This is the basis for the discussion of prioritizing, combining and refining in this final meeting. This is important because you will prioritize no more than six goals. In the last half of the meeting, you will develop strategies and outcome measures.

Strategies

In completing the strategies section, the task force records what needs to be done to complete each goal. It is more important to be clear than comprehensive at this point. There will be ample opportunity (and need) to fine-tune during implementation. That level of detail happens later.

Outcomes for the Community

In this section, the task force indicates what needs to be in place for the community to know that this goal is completed. Writing action steps and outcomes are simple tasks; however, there are a few guidelines that you should be aware of before you start writing. We'll start with action steps.

- **Action steps:** These are your "to-do" list. They take you from the goals you wrote down on paper to real-life outcomes. Action steps don't have to be fancy or complex; in fact, keeping them as simple as possible is best, because this makes them easier to achieve. Including a timeframe is another helpful tip. For example, "Read evidence-based practice articles by Friday" gives you a simple, achievable task with a deadline that helps fight procrastination. Each action step you complete brings you one step closer to the desired outcomes.
- **Outcomes:** These give you a picture of what your overall goal will look like when it has been achieved. Remember that these outcomes are the plan that your task force has created. Don't limit yourself to one outcome per goal. If you feel that your goal needs multiple outcomes, by all means write them! Well-written outcomes are observable and measurable. An example of an outcome might be "Our community will have active providers of at least three evidence-based practices." Finally, avoid using words that are difficult to observe and measure (e.g., understand, appreciate or learn). Remember that the action steps and outcomes you create will be unique to your community. An action step or outcome from one community is not transferable to another community, given its unique needs and resources.

Tasks for the Sixth Meeting

- Complete the plan section.
- Develop strategies for completion.

- Identify practical outcome measures.
- Determine what the task force should do in the future.

Outcomes of the Sixth Meeting

- Final edits on the plan
- Discussion and distribution of the community plan to task force members and beyond

Section 6: Community Plan

General Goals List

Specific Goals	**General Goals**
Example: We need to train volunteer coaches on recognizing autism.	Example: We should do more to include all children in our sports program.

Community Plan Example

Goal:	**Strategy:**	**Outcome:**
Train all volunteer coaches in city leagues on recognizing autism.	• Build a 30-minute training and make it part of coaches orientation • Provide bulleted information on autism printed on team rosters.	• At least 75% of coaches trained. • All team rosters printed with Info bullets.
Goal 1	**Strategy**	**Outcome**
Goal 2	**Strategy**	**Outcome**
Goal 3	**Strategy**	**Outcome**
Goal 4	**Strategy**	**Outcome**
Goal 5	**Strategy**	**Outcome**

What Happens Next?

Now the task force decides next steps. For example, the plan could result in each member taking what they have learned back to their sector of the community, or the task force could commit to continue meeting and begin implementing the plan. At this point it becomes,what any particular community wants to make of it.

Whatever direction you take, to leave the plan for others to follow or to continue working to make it a reality yourselves, you will want to share your results with your community, interested parties and stakeholders, as well as people who can help support your goals. Think about what parts of your process you wish to share. You can create a summary document, or you could make part or all of the Assessment and Planning Toolkit available for people to review. You can tell people how to view your work through social media such as a website, Facebook or Twitter. You may want to consider planning formal presentations, focus groups or town meetings to gather input on the plan. Copies should be sent to local governmental and nonprofit entities such as school districts, advocacy groups, the chamber of commerce and civic associations. You should also send a copy to police and fire department leadership and city and county government.

This blanket communication is important because it shows up on the radar. It tells local leadership that you are serious. Most importantly, it creates connections. For example, your plan may call for first-responder training in ASD, so you will need to talk to the police chief to make that happen. In other cases you may not have thought about how to involve the police, but creating some familiarity with the chief may create a social connection that can be useful later or connects you to other community entities you want on your side.

You may have created goals or tasks that need to be handed off to someone else. Perhaps your community needs to increase capacity for a particular type of service, or you have suggestions on how to improve the Medicaid Waiver. Your team needs to get your plan to the people best suited to get those things done, such as a government agency or a provider association.

To summarize:

- Decide if you will stay involved or end your work as an advisory task force.
- Communicate your work to interested parties, supporters, stakeholders, and the general community.
- Identify tasks you want others to take on and talk to them.
- Talk to powerful people, even if you don’t have an immediate job for them to do, as you build connections throughout your community.
- Make recommendations to government and other professional groups who can contribute to the goals identified in the plan through specific actions.

When preliminary communication is done, it's time for the team to start thinking about how to implement the plan. Many times, the people who were important in assessing and planning are not the same people needed to get things rolling. You need people who have influence to make things happen, either through their role in the community (e.g., the police chief or someone high in that department) or the relationships they have. You may also want a shift in the personalities; creative, idea people excel at some tasks, while detail-oriented doers excel at others. These are some things to consider when making these decisions and planning next steps.

Formal vs. Informal

The community assessment and plan are completed as a working document. At the end of the process, the task force has six goals to work on. The general list of goals provides the basis of the next generation of activities. Remember that the more time that passes, the more important it is to revisit each goal, instead of moving ahead with implementation without determining they are still relevant or practical. The task force (or other entities) may want a formal document of the process and the plan. This is worth considering, as such documentation can legitimize the process and garner future support. For example, the worksheets can easily be translated into a formal document, but this task should be made one of the specific goals so that resources can be secured. Regardless, the worksheets should remain a working document within the task force meetings so that the plan stays flexible and can be updated and changed as needed.

The Role of Government

Many of your goals, especially some specific ones, will require government action (increased capacity or funding; changes in law, rule or policy; etc.). This provides a great opportunity to build or reinforce an advisory relationship between community leaders and government entities concerned with services for people with autism or other disabilities. As the task force progresses from planning to doing, the relationship among its members changes, and sometimes drops off. The relationship with government entities may be the most important to maintain. How to develop and maintain that relationship will need to be discussed and planned.

The Future of the Champion and Task Force Members

The Champion has been the central servant-leader throughout this process. The task force members have been a committed part of the venture as well. This group should think about what happens next with regard to their specific roles. This process may have been intense. Volunteers need an opportunity to decide when they have fulfilled their obligations and want to back out of the process. The transition from planning to doing provides a natural pause during which task force members can reflect on their involvement and the future membership of the group. However, at the same time, it presents the pitfall of discontinuity. That is, things can grind to a halt without anyone realizing it. Therefore, it is important for the task force to engage in explicit, honest conversations about the best way to navigate this part of the journey and keep going.

Subcommittees and Other Structural Considerations

One possible format for continuing the work of the original task force is to create subcommittees. These would be additional teams led by members of the original task force that take on implementation of particular goals, including recruiting a fresh set of volunteers. The advantage of this approach is that it helps prevent burnout and the tendency to lose sight of particular goals. It is hard work, however, and takes time and commitment.

The task force should guard against goals having to do with a particular sector being segregated to subcommittees. Community is not built or reinforced by creating isolated pockets of activity that do not communicate with others. For example, a committee that develops training for first responders, which then sits unread on a shelf because no one involved first responders to make sure it is useful, may seem far-fetched, but this type of thing happens all too often. It is important to make sure that the task force involves the comments or feedback of those for whom their plan is intended.

In reality, this working plan is constantly in development – changing and responding to new information, new opportunities and new challenges. Remember, the most important thing the community gets from this process is not the plan; it is the commitment to make a better future for the members of your community who have autism or other disabilities. That is the promise of this process. The toolkit will get you started, but commitment and passion are the driving forces. The first steps are done. The real work, as well as the real rewards, begins now.

Additional Readings and Resources

Readings

- *The Abundant Community: Awakening the Power of Families and Neighborhoods*, by Peter Block and John L. McKnight
- *Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*, by John McKnight and John Kreztmann
- *Community: The Structure of Belonging*, by Peter Block
- *Constructing Disability and Social Inequality Early In Life Causes*, by Justin Powell
- *Getting to Yes*, by Roger Fisher and William L. Ury
- *In Search of Excellence*, by Tom Peters and Robert H. Waterman
- *The McKinsey Way*, by Ethan M. Rasiel
- *Social Work Macro Practice*, by F. E. Netting, P. M. Kettner, S. L. McMurtry and M.S. Thomas
- *Willpower: Rediscovering the Greatest Human Strength*, by Roy F. Baumeister and John Tierney

Resources on Community Building

- Appreciative Inquiry: http://appreciativeinquiry.case.edu
- The Art of Hosting: www.artofhosting.org
- The Asset-Based Community Development Institute: www.abcdinstitute.org/profile/?ProfileID=47&/JohnMcKnight/
- The Community Toolbox, University of Kansas: http://ctb.ku.edu/en/default.aspx

Resources on Team Building

- *The Big Book of Team-Motivating Games: Spirit-Building, Problem-Solving and Communication Games for Every Group*, by Mary Scannell and Edward Scannell
- *Harvard Business Review on Building Better Teams*, by Bob Frisch
- Team Building: A Complete Guide: www.teamtechnology.co.uk/tt/h-articl/tb-basic.htm
- *Team Building: Proven Strategies for Improving Team Performance*, by William G. Dyer, Gibb Dyer, Jr., Jeffrey, Dyer, and Edgar H. Schein
- Unique Team Building and Training Resources: www.teambuilding-resources.com

Resources on Autism and Disabilities

- Autism Internet Modules (free Internet-based training on autism): www.autisminternetmodules.org
- Centers for Disease Control and Prevention: www.cdc.gov/autism
- Centers for Medicare and Medicaid Services: www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf
- The Center for Systems Change, Disability Policy and Social Welfare: www.centerforsystemschange.org
- National Autism Center, National Standards Practice: www.nationalautismcenter.org/about/national.php
- National Professional Development Center on Autism Spectrum Disorders: autismpdc.fpg.unc.edu/content/briefs
- Ohio Center for Autism and Low Incidence: www.ocali.org
- Texas Autism Research and Resource Center: www.dads.state.tx.us/tarrc/
- Texas Council on Autism: www.dads.state.tx.us/autism/
- Texas Statewide Leadership for Autism Training, including TARGET: Texas Autism Guide for Effective Teaching: www.txautism.net

Appendix A:
Anytown, TX

Anytown, Texas

The first of the following narratives, Dispatches From the Real Word, is a real-life account of a community in New York. Some of its members saw a need and did something about it. It's a great example of how community change happens: from within, naturally – and with an eye to a better future.

The Texas Community Assessment and Planning Toolkit empowers and supports naturally emerging commitment to changing something for the better with a process that helps bring about the desired change. Outside tools cannot make change happen. They can only help with organization and structure. If there's too little help, the passion fades; if there's too much help, the passion is smothered. The key is balance.

The second narrative, Anytown, Texas, is a sample profile, based on a variety of real communities, including the New York vignette. This models the kind of information that is useful when applying the toolkit to an actual community.

Dispatches From the Real World: The Story of AHA of New York, or How to Grow an Action Group, One Family at a Time

In 1988, Dr. John Pomeroy was conducting research on children with high-functioning autism at the University Hospital of Stony Brook. In the course of his work, Dr. Pomeroy stumbled on a problem: The families participating in his study, feeling stressed and isolated, lacked a supportive place where they could share their experiences with other families. They also needed a way to gain resources about children with high-functioning autism. Unfortunately, no organization in the community provided such services.

Dr. Pomeroy decided to do something about it and created a support group for the parents who participated in his study. Together, they became the Advocates for High-Functioning Autistic-Like Children. After a year of support and encouragement from Dr. Pomeroy, the group set off on its own.

From their beginnings as a small support group for families, Advocates for High-Functioning Autistic-Like Children, now called Asperger Syndrome and High Functioning Autism Association (AHA), has grown into a nationally recognized organization that involves more than 3,500 people. Today they offer 12 monthly support groups for families and individuals; host family, community and fundraising events; distribute a newsletter to more than 700 people; and provide general assistance to families and individuals who seek help. Getting to this point has taken more than 20 years. Like any other organization, the group continues to be confronted with the challenges of running a non-profit organization.

How Did They Do It?

When AHA began, its members met in coffee shops, in basements – wherever they could find a free space to meet. This no-frills, grassroots strategy worked well for many years. They relied on the time and energy of passionate people to make the organization what it is today. AHA is almost entirely led by volunteers. Currently, they have two part-time employees; everyone else works for free. Recently, they began using people with autism to help support the organization. A group of students with Asperger's disorder worked as interns helping with web and technology development. Another major resource AHA has used to build its organization is simply making connections and building relationships with other people. Members looked to leaders in the field -- for example, Tony Attwood and Peter Gerhardt, to give them guidance and support, and they connected with other parents to get the word out.

They partnered with local businesses by offering free services to support employees with AD. And they approached organizations that provide complementary services about joining forces, in addition to partnering with organizations doing similar work in other areas of the country. Two of their current partners are Global and Regional Asperger Syndrome Partnership (GRASP) and Spectrum Services. GRASP is a peer-run support group with chapters across the country. Spectrum Services is a collaborative of psychiatrists, psychologists, occupational therapists, speech therapists, social workers and college coaches in New York City. AHA also attended local fairs, support meetings, hotlines, class lectures and community talks to get others involved. Essentially, AHA talked to anyone who would listen.

By the 1990s the group had gained enough of a following to host its own conference(now in its 22nd year). This conference teaches educators how to work with children who are high functioning. When it started, this was the only professional development opportunity in the area, including New York City, that addressed issues related to high-functioning autism. Twelve years passed before anyone else in the region did anything similar. During this time, the group gained a substantial following. The group started its second conference in the spring 2000. In 2000, AHA also created its first website and moved into its first office space.

It's All About Your Network

The Internet has also been an important resource for AHA. When the group first began, they used Yahoo Groups to connect parents and to publicize information about their group. This has now been replaced by Constant Contacts, which is used to send out weekly communications to members. The website provides information about services and events, and how to connect with the group.

Running an organization also means raising funds to support and sustain services and programs. AHA looks for money everywhere possible. Most of the funding comes from parents and families that the organization has helped. At the end of each year, AHA appeals to its members for funds to support the organization. Finally, all members are charged a fee -- $40 for a year membership, $70 for a two-year membership, and $400 for a lifetime membership.

Other funding sources include Autism Speaks, private donors, and corporate sponsors. Finally, AHA hosts a number of fundraising events throughout the year. The main event is called Rock and Bowl. People purchase tickets to bowl and can also purchase raffle tickets to win prizes such as iPads or weekend trips. For a fee, individuals, families and businesses can sponsor a bowling lane, or even the entire event itself.

What's Next?

Although AHA is very successful, it faces challenges. As is the case for most nonprofit organizations, raising funds is difficult. AHA does not have a steady or reliable source of income; it depends solely upon donations. A plan for sustainability is another challenge. Running an organization with volunteers may be feasible for the moment; however, such a strategy may not work in the future. AHA would like for the group to get more grants, do more fundraising, and be more realistic in terms of staffing to promote the sustainability of the organization.

Despite these issues, AHA has been successful for more than 20 years. Leaders have been successful because they saw a void in the current system and used the drive and persistence of passionate people to fill it. The organization has also been flexible about meeting the needs of the community. Over the years, its focus has shifted from solely supporting children to supporting people of all ages.

To sum it all up: This story simply starts with one invested professional and a group of dedicated community members. As it grew, the organization saw changing needs within the community and adjusted itself to reflect and meet those needs.

Thanks to Pat Schissel of AHANY for providing information for this article.

Sample Profile: Anytown, Texas

Meeting 1

Section 1: The Task Force

The Champion	Jami Conner, jamic@aol.com
The Recorder	

The Task Force

Name	Phone	Email
David Tully, parent	555-6823	dtully@texcom.net
Mark Tully, personwith autism	545-3881	mstully@texcom.net
William Jamesen, insurance	555-1243	wjamesen@jameseninsurance.com
Alan Woodford, Big Bank, Inc.	555-6211	Alanw23@yahoo.com
Amanda Lopez, graduate student	545-8712	amandaplease@ots.edu
Jack Smith, provider	555-1819	jsmith@hopecenter.org

Summary of Meetings

Meeting	Content	When	Where
Meeting 1	Getting ready	all meetings @ 7:00 pm	Jami's House (will email address)
Meeting 2	Our community	6/12/11	Rec Center
Meeting 3	Services	7/14/11	Rec Center
Meeting 4	Six Conversations	8/22/11	Rec Center
Meeting 5	Planning	9/9/11	Rec Center
Meeting 6	Wrapping up	10/15/11	Rec Center

Meeting 1: Summary of Guiding Questions

These questions direct the discussion. In these first meetings, the conversation may seem awkward. Be patient. Part of what these discussions do is help build relationships. As team members get to know each other, it will get easier.

- **What do we "know" about people with autism and other disabilities?**

  Mark really helped us understand what it's like to live with autism in our city. There are lots of things that aren't problems or barriers for us but that can be daunting for people with autism – everything from traffic noise to not understanding the small jokes from waiters and then getting bad service as a result. Mark says it's easier to just stay home.

Bill says his sales staff is trained to build rapport with people through humor. He never realized that can hurt relationships in some cases. Bill said, “I know a pretty good amount about autism because of my niece, but I never looked at it that way before.”

Mark said he takes classes at the community college, but he has no job and spends most of his time at home.

- **Are there things we don’t know, or do we have information that might be based on inaccurate data?** This is an opportunity to explore misconceptions about autism and other disabilities and people who struggle with them.

  After Mark’s talk, Alan said he didn’t really know much about autism and asked for some material. Dave and Mark gave him some websites. I added that there was a list of references in the copy of the Toolkit I handed out to everyone. Most of the team has some interest in and knowledge about autism because of a friend or relative.

- **Do we have any doubts about our ability to fully integrate people with disabilities into our community?** This question allows the group to further explore presuppositions. Can people with disabilities be productive employees?

  We all shared a lot of doubts about our ability to do this, and some asked if there were government programs that should be doing this. As parents, Dave and I told the group that there are lots of government-funded programs and services that help families and individuals a great deal. Jack also chimed in as a provider. But even with all that, our children with autism seem much more isolated than do our other children, a fact that Mark’s story confirmed. Also, parents can feel isolated with demands that make it hard to function like a “normal” family. It is difficult to get information, and then it is difficult to judge if the information is good and trustworthy.

  I told the group about how I discussed this problem with my daughter’s case manager, who told me about this Toolkit. Some in the group are still skeptical but we all decided to give it a try.

  p.s.: Amanda volunteered to do the homework for the second meeting.

Meeting 2

Section 2: Community Assessment

Describe your community. Is it a small town or a suburb; an urban neighborhood or a rural township?

Suburban community

What is the population of your community? (You may need to estimate here, and that’s fine.)

We know exactly now!! In our city – 38,703; in the area – 85,634. This made us wonder if we should have a larger group?

Is your community ethnically diverse? Multilingual? (This is important to get to eventually as you think about the things you plan to do as a result of this work. For example, if you print resources, you may need to think about translations. For now, though, it's most important that you have an overall sense of your community that you all agree on.)

The chamber of commerce information we have doesn't have details of racial or ethnic diversity. Some of us thought our city is pretty diverse but others don't think so. We agreed that we don't have any large, specifically ethnic neighborhoods.

Residential/housing. Describe the housing available in your community. Do you have a variety of housing (houses, apartments, etc.)? Does your community have low-income housing? How does your community deal with homelessness?

We have a wide variety of housing available. We have some relatively cheap apartments in town and more in the surrounding areas. We don't have any public housing projects, but we do have retirement villages, nursing homes, and group homes. The city has a homelessness problem, but it doesn't seem to have reached our community though we have heard that some food pantries in our town have become very busy through the recession. Jack suggested that we assume that poverty and housing issues have hit some members of our community harder than is apparent.

Business. Does your community have a thriving business sector or is it struggling? What is the unemployment rate for your county? Does your community have a variety of jobs, like manufacturing, or are there mostly service jobs, for instance, in hotels or restaurants? Remember, people with autism and other disabilities often have difficulties with transportation, so think about the job situation right in your community, not in outlying areas that may be difficult to reach transportation-wise.

We have all sorts of businesses, from services to light manufacturing. According to the chamber of commerce, finance and insurance are our biggest sectors, and sales is our number one occupation. Alan pointed out that we have lots of thriving restaurants, and he has heard from a realtor friend that we have a low level of unoccupied office space, which is good.

Arts /entertainment. What kinds of outlets for arts and entertainment does your community have? Do you have a community arts center? Does your community have restaurants or movie theaters? Can you identify where young people hang out?

Evidently we have five art galleries or museums. However, between us we could only think of three! Amanda knows of a community theater group and a community orchestra.

Social/recreational. Does your community have recreational centers free to the public or relatively inexpensive, such as a YMCA? Are there outdoors athletic venues, such as basketball and tennis courts, a public pool, or a skate park? Does your community have indoor options, such as a bowling alley or an arcade? Does your community have organized athletic associations for children and adults? Does your community have an active Special Olympics chapter?

We have plenty of organized sports, especially for kids, but we also have a few adult leagues and clubs for softball and soccer. We have lots of parks and a relatively new rec center, where we are meeting. Mark said this is the first time he's been in it and it's not as bad as he thought it would be. We were all surprised at his comments, so he explained how large busy buildings can sometimes be overwhelming. He also said that he had never been involved in organized sports, though he played with his brothers while they practiced. He said, "Sports leagues are not really that friendly to kids like me."

Cultural/religious. Does your community have a variety of houses of worship? Are the houses of worship active in your community (i.e., sponsor or participate in civic events)?

Between us, we could think of lots of churches of all sorts of denominations. Amanda pointed out that she was not aware of any houses of worship from other religions in our community though there were some located nearby.

Education. Do the schools in your community offer extracurricular activities? Do the high schools in your community offer vocational and job training programs? What about higher education? Do you have a community college or a four-year institution in or close to your community?

Great school system – rated as "excellent" by the state. Nine colleges and universities in the area.

Medical care. Does your community have doctors or clinics that serve your community or do you have to go elsewhere for health care? Do you have a hospital nearby? Does your community have specialists, such as psychiatrists nearby? Do you have physical therapy or speech-language therapy nearby or do you have to go elsewhere ?

Our community has a full-service hospital, a number of clinics and specialty health centers. We have 178 practicing doctors in our community. Amanda calculated this to be a ratio of 1 doctor for every 218 people. We also have the children's hospital autism center in our community.

Meeting 2: Summary of Guiding Questions

These discussion questions may seem general and off-topic. Trust the process, and remember that a community that is good for people with disabilities is a community that is good for all its members.

- **Having reviewed the information presented, do we feel generally positive or generally negative about the community?** Do you think your community is a well-rounded, good place to live? If so, why? If not, how could it be better?

  The information that Amanda got from the chamber of commerce was great. We agreed that we have a pretty well-rounded community and are very lucky in many ways. If anything, we have a problem with information and communication – all of us were surprised at the resources we have in our own back yard.

Also, thanks mostly to Mark's contribution, we now have a better understanding of how some things in our community are great for most but leave some of our members out. Dave and I could relate to this better than some of the others. Alan and Bill agreed this was a rude awakening for them.

We are starting to gel as a group.

- **Think about "what we have" and "what we would like." Are they linked?** If not, how can we help to link them?

We talked about support and the ways we interact with each other as members of the same community, even with folks we don't know. Bill said these conversations were making him think more about his customers as different people with different situations. He added, "It's easy for me to think about customers in groups by the type of insurance coverage they need. This opens up all sorts of responsibility. Jami, you are my customer and I've learned more about you in the past few minutes than I've known about you over the past few years. I just can't imagine what it's like – Dave, Mark – same thing. I just can't imagine it."

Bill and Alan had a lot of questions for the rest of the group, especially Jack as a service provider, about what kinds of services are available. This was a great place to close the evening after two hours.

Jack took the homework for next week.

Meeting 3

Section 3: Assessment of Services

Naturalistic play-based or developmental relationship-based interventions

These services take place primarily in natural settings, fit into everyday routines, and have a strong focus on social interaction and building relationships.

Examples include …

- P.L.A.Y. Project (Play and Language for Autistic Youngsters)
- DIR models (Floortime) (Developmental, Individual Difference, Relationship-based Model)
- Responsive Teaching
- RDI (Relationship Development Intervention)
- SCERTS (Social Communication, Emotional Regulation, Transactional Support)

Does your community have these types of services?

No	[✓ **Yes, very little**]	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

We were not completely sure what this was, but Amanda knows a family who connected with a P.L.A.Y.-certified provider for her 2-year-old after she and her pediatrician noticed some delays. She swears by it.

There doesn't seem to be any other providers of this kind of service in our community. All agreed that we should look into this further, especially for very young children.

Behavioral interventions

These interventions can be moderate to intensive and range anywhere from a few to 40 hours a week. They are designed to increase functional behavior and decrease maladaptive or undesirable behavior.

Examples include …

- Modifying the environment
- Applied behavior analysis such as discrete trial training
- Pivotal response training
- Incidental teaching
- Specific instruction

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	[✓ **Yes, a lot**]	**Don’t know**

Discussion

ABA services – We knew of three or four major providers of ABA, including children’s hospital, before we looked at the list Jack provided from his Google search. Dave and I are very familiar with this service. It’s evidence-based, but very expensive.

Integrated physical medicine

These are physician-based medical interventions that take a whole-body approach.

Examples include …

- Chiropractic medicine
- Osteopathic medicine
- Cranial sacral therapy
- Massage

Does your community have these types of services?

No	[✓ **Yes, very little**]	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

A Google search could not distinguish pediatricians' practices from other types of physicians, so Jack could offer no information on this. My pediatrician is different, so I talked about her for a minute. She recommends supplements to our diets and has suggested some changes to organic foods and ways to decrease exposure to chemicals.

She says the chemicals usually aren't harmful, but we know so little about how autism occurs in the brain, and it won't hurt us not to have the chemicals, so why not give it a try? I don't know if it works, but my daughter has done much better since we started seeing this doctor.

Biomedical interventions

This includes other medically oriented alternative approaches.

Examples include …

- Special diets (such as gluten- and/or casein-free)
- Use of specific vitamins and/or supplements

Does your community have these types of services?

No	[✓ **Yes, very little**]	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

Jack found lots of information on this but knows only one practice that provides biomedical interventions locally. We decided to circle "Yes, very little" because of my pediatrician, but it doesn't really fit.

Additional therapies

These are license- or certification-based therapies not specific to autism but considered by many to be very helpful.

Examples include …

- Speech-language therapy
- Occupational therapy
- Physical therapy
- Music therapy
- Art therapy
- Sensory therapy

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	[✓ **Yes, a lot**]	**Don't know**

Discussion

There are several clinics that offer these services, including for injuries, sports medicine, rehab, etc. Children's hospital offers most of them. Some were harder to find and are not in our community but very close by, like music therapy. Sensory therapy is not available by itself that we could find, but it is part of many school and other programs.

Alternative therapies

These are additional established therapeutic interventions, not specific to autism but considered by some to be helpful.

Examples include …

- Therapy with animals (horses, dogs, etc.)
- Aquatic therapy
- Acupuncture
- Other alternative therapy

Does your community have these types of services?

No	[✓ **Yes, very little**]	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

There are a few acupuncture places in the city but none specifically for people with autism. There appear to be limited equestrian therapy services offered through some riding stables around this part of the state.

Assistive technology

This includes any adaptive equipment or use of technology that research has found to be helpful or is just beginning to explore.

Examples include …

- Adaptive equipment
- Specific instructional materials
- Assistive technology devices
- Computer
- Communication device
- Touch screen
- Picture communication systems

Does your community have these types of services?

No	**Yes, very little**	[✓ **Yes, some**]	**Yes, a lot**	**Don’t know**

Discussion

This has really opened up recently. It used to be, Dave reported, that the stuff was so expensive that you could only get it through school (and then they would keep it at school) or Medicaid, if you were eligible. Now Mark has an iPad and has downloaded a lot of apps that are very helpful. There are even websites that review educational apps made specifically for people with autism.

Jack also reported that some agencies have equipment lending libraries. Technology is changing so much. Equipment that is not developed for general use, like the tablets anyone can get, is quickly out of date.

Meeting 3: Summary of Guiding Questions

- **Do we hear stories of people with autism going without services?**

  Yes. We hear of families not getting services because they can’t afford them, and there is no help.

- **Does our community have a wide range of services available for people with autism?**

  We appear to have a wide range of services available, either in our community or close by. We are lucky to have the autism center in our town. A few of us know of families from rural communities who do not have the services we have.

- **Think about “what we have” and “what we would like.” Are they linked?** If not, how can we help to link them?

  The information Jack provided came from a database of providers obtained from a state agency and Google searches. He said the problem is that having a list of all the service providers really doesn't help much. If you sort by location, I could find a provider in my town but farther away than another provider in another town.

We ended up arriving at two conclusions.

First, there is a lot of information on services available but it's confusing. Dave told the story of finding services for Mark when he was young, only to learn that he was not eligible or there was a waiting list. Jack suggested that one of our goals be to get the state to develop a clear, sortable database for services available throughout the state. That would help parents, individuals and providers, he said.

Second, after our discussion we realized that parents need a network they can use in a semi-organized yet effective way, sort of like an informal Angie's List. Jack said he knew a researcher at the university who had observed in his research with families with children with disabilities that parents lack a basic forum to talk with others who are having similar experiences. We all agreed we should think about that.

Meeting 4

Section 4: The Six Conversations

The Six Conversations

Conversation 1: The Invitation

A Brief Explanation

The first conversation is an invitation. In your planning process the "invitation" conversation began in the first meeting. As you read this now, the task force has a bit of history, and working relationships have emerged. Still, it is a good idea to start this meeting with a welcoming invitation. You might ask how the group is doing, and encourage honest answers. There is no need to document the answers unless you want to. Although it may feel unnecessary at first, this is a good opportunity to revisit the point of the project – to welcome people with autism into the community – and to reinforce how recognized and valued we all feel when we are genuinely and explicitly invited to be a part of something. Reflection on this may help renew enthusiasm and empathy in the task force's work.

Conversation 2: Possibilities

- For you as an individual, what does our community look like when we are finished? In a year?
- What do we want to create together that will make a difference?
- What can we create together that we cannot create alone?

Alan summed up this part of our discussion best. He said he keeps coming back to how many times Dave and I mentioned being isolated. "I don't know how to do it," he said, "but I think it would be nice if everyone in our community had the kind of comfortable support that these meetings have come to be for me."

Conversation 3: Ownership

- How valuable do you plan for this project to be?
- To what extent are you invested in the well-being of the whole community?

We've all lived in this community for a long time and take great pride in it. The notion that some don't feel like that or don't feel welcome bothers us. We have really come together as a team and want to see change. We want a more supportive community.

Conversation 4: Dissent

- What lingering or emerging doubts do you have?
- Have you said yes to something you don't really support?
- What differences do we have among us about this project?

Nobody dissented, but we still don't know how to do this. We don't even know what we're doing yet. We know we haven't got to that part of the Toolkit yet, but we all agree this part is hard! I think it's fair to say that the doubts we felt about our ability to do this when we first started are coming back.

Jack said he had read one of the books on the reference list, the book with the Six Conversations. Based on that, he said it's natural that we struggle with these "conversations" and that going through them helps us move through all the confusion, doubt, and fear. It doesn't fix it all; it just gives us a chance to live with it and get used to it.

It sounds kind of like starting a business. You think, "I can't do this; other people can, but not me." Then you get to a point when you just do it even though it feels like you have no idea what you're doing. It is fortunate that we all support the project and are of the same mind.

Conversation 5: Commitment

- What commitment are you willing to make?
- Are you ready to risk failure and start again?
- Are you ready to risk success?
- What story about your community do you most identify with?
- Are you ready for that story to change?

It sounds weird, but our conversation about commitment came right out of our discussion of doubts. We really did get to a point where we understood the risks and that it was an uphill climb, but we all felt ready to do something and felt we were in a better position to figure out what that something is.

We are all willing to make a reasonable commitment, but we are not yet sure what reasonable means. We know that we want to succeed, yet we have decided that if we fail we will use what we learned to begin again.

We agree that the status quo is not allowing people on the spectrum to become "all that they can be." And we are ready for that to change. It is important to everyone that individuals on the spectrum have supports they need to become contributing members of society. They also deserve to feel that they are welcomed members of the community.

Conversation 6: Gifts

- What gifts have you received (personally or for this process) from members of this task force?
- What gifts have you given in return?
- How can you focus on gifts and abilities in your work? In your life?
- Would you rather be known by the gifts you present, your abilities, or by the problems and inconveniences you cause?

Bill said this conversation felt like the end of the process but then he realized that we don't even have a plan yet. At the same time, this was a good exercise, he said. He admitted that he was skeptical at first, but he thinks we are ready to get down to work.

We went around the room at Amanda's suggestion and all ended by saying something that we personally had gotten out of this process so far. It was very nice.

Meeting 5

Section 5: Activities of Community Life

	Earner	Buyer	Participant
Access			
Communication			
Socialization			

Meeting 5: Summary of Guiding Questions

- **How can we support people with autism as earners?**
- **How can we support people with autism as buyers?**
- **How can we support people with autism as participants?**

We had a great discussion about the activities and dimensions of community life. Some of us were relieved to get at something more concrete. It made sense that we think about people with autism as members of the community first and then identify where the community can be more helpful to them in accessing it.

Mark summed it all up. "If I have a job, I buy more stuff, pay taxes. Even if some people think I'm odd, that doesn't matter. I get something and get to contribute."

- **List any general goals that have emerged from the Six Conversations and the discussion of community life.**

  Examples:

  Our community has a strong youth sports program. Maybe we can do better and include everyone.

  This is what we came up with …

  1. Families need to know what services are available.
  2. Businesses should have the information they need to tailor their business toward people with autism and other disabilities.
  3. Parents seem isolated. They should have a way to connect with others and get support.
  4. Our businesses should hire our own members. How can we get word and training out to employers? Maybe the chamber of commerce can help.
  5. Vulnerable people should feel safe. We need to review our parks for safety and train police, EMTs, and firefighters.

Meeting 6

Section 6: Community Plan

General Goals List

Specific Goals	**General Goals**
Example: We need to train volunteer coaches on recognizing autism. • Compile database of area services • Create forums for parents to connect with each other. • Train local business on how to hire people with autism. • Train first responders on autism. • Create "safe zones" in a few parks for families with a child with autism.	Example: We should do more to include all children in our sports program. • Increase knowledge of community. • Build a more supportive community. • Have community events to raise money and awareness.

Community Plan

Example Goal:	**Strategy:**	**Outcome:**
Train all volunteer coaches in city leagues on recognizing autism.	Build a 30-minute training and make it part of coaches orientation. Provide bulleted information on autism printed on team rosters.	**At least 75% of coaches trained.** **All team rosters printed with information bullets.**
Goal 1	**Strategy**	**Outcome**
Recommend to the state that they develop a database of services that is accurate, user friendly, and statewide. May consider talking to our state representative.	Send a letter that spells out the need for such a database and shows how everyone would benefit.	We can't control the state, so we will measure our success by whether or not we get a response. We'll ask for a response and keep sending our request until we get one.
Goal 2	**Strategy**	**Outcome**
Create a support network for parents so they can find other parents with kids on the spectrum the same age as theirs for support and friendship.	Hope Center will team up with Jeff Smith from the university to create and host a network. They will gather resources (funding, space, website, etc.) and have them available for a small group of parents to build on.	Parents with children with autism will get information about support groups near them when their child is diagnosed. Hope Center will report of growth of network.
Goal 3	**Strategy**	**Outcome**
Increase employment opportunities for people with autism.	Jack, Alan, and Bill will develop a business-oriented training, and Bill will get the chamber of commerce to sponsor trainings for local businesses. Amanda will investigate program models for kids leaving high school to help transition.	We have to figure out how to measure this. For now, the team will collect stories on people getting jobs. The state might be able to help with this.

Goal 4	Strategy	Outcome
Get training for first responders on the basics of autism.	See if the state knows of any curriculum. If not, set up a work group, including police officers, EMTs, firefighters, and people with autism, to build one.	Ensure all first responders in our community receive training within a year.

Here's How the Story Ends…or Does It?

After creating this plan, group members discussed how they wanted to proceed. Everyone agreed that the initial work was complete, but now they needed to follow through with implementing and evaluating steps to determine if they'd met their goals, revising or adding goals as needed, and so on. Most members decided to stay on, though Amanda had to drop out when she graduated. The group recruited Jess, a provider, and Susan, wife of the local police chief who had been active in local causes. The newly repurposed group set some short-term goals to publicize the results of the work group, including a report that was available through a link on the chamber of commerce website and a month-long display at the library. They also set a goal to reach out to influential community members to gain awareness and support, including a grant writer.

Toolkit Blank Forms

Section 1: The Task Force

The Champion	
The Recorder	

The Task Force

Name	Phone	Email

Summary of Meetings

Meeting	Content	When	Where
Meeting 1	Getting ready		
Meeting 2	Our community		
Meeting 3	Services		
Meeting 4	Six Conversations		
Meeting 5	Planning		
Meeting 6	Wrapping up		

Meeting 1: Summary of Guiding Questions

- **What do we "know" about people with autism and other disabilities?**

- **Are there things we don't know, or do we have information that might be based on inaccurate data?**

- **Do we have any doubts about our ability to fully integrate people with disabilities into our community?**

Community Profile
Describe your community. Is it a small town or a suburb; an urban neighborhood or a rural township?
What is the population of your community? (You may need to estimate here, and that's fine.)
Is your community ethnically diverse? Multilingual? (This is important to get to eventually as you think about the things you plan to do as a result of this work. For example, if you print resources, you may need to think about translations. For now, though, it's most important that you have an overall sense of your community that you all agree on.)
Residential/housing. Describe the housing available in your community. Do you have a variety of housing (houses, apartments, etc.)? Does your community have low-income housing? How does your community deal with homelessness?
Business. Does your community have a thriving business sector or is it struggling? What is the unemployment rate for your county? Does your community have a variety of jobs, such as manufacturing, or are there mostly service jobs, such as in hotels or restaurants? Remember, people with autism and other disabilities often have difficulties with transportation, so think about the job situation right in your community, not in outlying areas that may be difficult to get to.

Arts and entertainment. What kinds of outlets for arts and entertainment does your community have? Do you have a community arts center? Does your community have restaurants or movie theaters? Can you identify where young people hang out?

Social/recreational. Does your community have recreational centers free to the public or relatively inexpensive, such as a YMCA? Are there outdoor athletic venues, such as basketball and tennis courts, a public pool or a skate park? Does your community have indoor options, such as a bowling alley or an arcade? Does your community have organized athletic associations for children and adults? Does your community have an active Special Olympics chapter?

Cultural/religious. Does your community have a variety of houses of worship? Are the houses of worship active in your community (i.e., sponsor or participate in civic events)?

Education. Do the schools in your community offer extracurricular activities? Do the high schools in your community offer vocational and job training programs? What about higher education? Do you have a community college or a four-year institution in or close to your community?

Medical care. Does your community have doctors or clinics that serve your community or do you have to go elsewhere for health care? Do you have a hospital nearby? Does your community have specialists, such as psychiatrists nearby? Do you have physical therapy or speech-language therapy nearby or do you have to go elsewhere?

Meeting 2: Summary of Guiding Questions

- **Having reviewed the information presented, do we feel generally positive or generally negative about the community?**

- **Think about "what we have" and "what we would like." Are they linked?** If not, how can we help to link them?

Assessment of Services

Naturalistic play-based or developmental relationship-based interventions

These services primarily take place in natural settings, fit into everyday routines, and have a strong focus on social interaction and building relationships.

Examples include …

- P.L.A.Y. Project (Play and Language for Autistic Youngsters)
- DIR Models (Floortime) (Developmental, Individual Difference, Relationship-based Model)
- Responsive Teaching
- RDI (Relationship Development Intervention)
- SCERTS (Social Communication, Emotional Regulation, Transactional Support)

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don’t know

Discussion

Behavioral interventions

These interventions can be moderate to intensive and range anywhere from a few to 40 hours a week. They are designed to increase functional behavior and decrease maladaptive or undesirable behavior.

Examples include …

- Modifying the environment
- Applied behavior analysis such as discrete trial training
- Pivotal response training
- Incidental teaching
- Specific instruction

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don't know

Discussion

Integrated physical medicine

These are physician-based medical interventions that take a whole-body approach.

Examples include …

- Chiropractic medicine
- Osteopathic medicine
- Cranial sacral therapy
- Massage

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don’t know

Discussion

Biomedical interventions

This includes other medically oriented alternative approaches.

Examples include …

- Special diets (such as gluten- and/or casein-free)
- Use of specific vitamins and/or supplements

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes, a lot**	**Don’t know**

Discussion

Additional therapies

These are license- or certification-based therapies not specific to autism but considered by many to be very helpful.

Examples include …

- speech-language therapy
- occupational therapy
- physical therapy
- music therapy
- art therapy
- sensory therapy

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

Alternative therapies

These are additional established therapeutic interventions, not specific to autism but considered by some to be helpful.

Examples include …

- therapy with animals (horses, dogs, etc.)
- aquatic therapy
- acupuncture
- Other alternative therapy

Does your community have these types of services?

No	**Yes, very little**	**Yes, some**	**Yes, a lot**	**Don't know**

Discussion

Assistive technology

This includes any adaptive equipment or use of technology that research has found to be helpful or is just beginning to explore.

Examples include …

- adaptive equipment
- specific instructional materials
- assistive technology devices
- computer
- communication device
- touch screen
- picture communication systems

Does your community have these types of services?

No	Yes, very little	Yes, some	Yes, a lot	Don’t know

Discussion

Meeting 3: Summary of Guiding Questions

- **Do we hear stories of people with autism going without services?**

- **Does our community have a wide range of services available for people with autism?**

- **Think about "what we have" and "what we would like." Are they linked?** If not, how can we help to link them?

The Six Conversations

Conversation 1: The Invitation

Conversation 2: Possibilities

- For you as an individual, what does our community look like when we are finished? In a year?
- What do we want to create together that will make a difference?
- What can we create together that we cannot create alone?

Conversation 3: Ownership

- How valuable do you plan for this project to be?
- To what extent are you invested in the well-being of the whole community?

Conversation 4: Dissent

- What lingering or emerging doubts do you have?
- Have you said yes to something you don't really support?
- What differences do we have among us about this project?

Conversation 5: Commitment

- What commitment are you willing to make?

- Are you ready to risk failure and start again?

- Are you ready to risk success
  - What story about your community do you most identify with?
  - Are you ready for that story to change?

Conversation 6: Gifts

- What gifts have you received (personally or for this process) from members of this task force?

- What gifts have you given in return?

- How can you focus on gifts and abilities in your work? In your life?

- Would you rather be known by the gifts you present, your abilities, or by the problems and inconveniences you cause?

Community Activities Grid

	Earner	Buyer	Participant
Access			
Communication			
Socialization			

Meeting 5: Summary of Guiding Questions

- **How can we support people with autism as earners?**
- **How can we support people with autism as buyers?**
- **How can we support people with autism as participants?**

Community Plan General Goals List

Specific Goals	General Goals

Community Plan

Goal 1	**Strategy**	**Outcome**
Goal 2	**Strategy**	**Outcome**
Goal 3	**Strategy**	**Outcome**
Goal 4	**Strategy**	**Outcome**
Goal 5	**Strategy**	**Outcome**

What's Next?

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