RESPONSE OF IDEAS

This package of materials is the collaborative effort of Advocates in Action, PAL and the Rhode Island Parent Information Network (RIPIN).

Advocates in Action is a Statewide Self-Advocacy organization. Each individual on our 17-member Board of Directors is person who has a Developmental Disability (DD). PAL is a family organization that is connected with people and family members who have DD across Rhode Island. RIPIN provides information, training and support to students with disabilities and their families to prepare them to be equal participants in the Individualized Education Program process, assuring a smooth transition from school to adult life.

Each of our organizations strives to help people who have a developmental disability and families learn how to speak up, make decisions and navigate the Service System. We're glad to contribute ideas about areas which may need improvement.

People from Advocates in Action, PAL and RIPIN attended both of the Summits that the Department of Mental Health, Retardation and Hospitals hosted in November 2007. When we heard about these Requests for Ideas, we spent some time talking about what the questions meant, and putting the information into formats that the people we're connected with could understand. We also talked a lot about what the term "Self-Determination" is all about.

We discussed these issues at our Board of Directors meetings and recorded the themes that people felt were most important.

Representatives from Advocates in Action took the same conversation to local Self-Advocacy groups around the state. At the same time, PAL hosted several informational meetings so that people who receive services and family members would have different opportunities to contribute to the conversation.

Our board members and staff also attended each of the Mini Summits hosted by MHRH. We listened to what people had to say and shared our own ideas.

In addition, Advocates in Action asked the 15 members of this year's Leadership Series class for their comments and input. The Leadership Series is a year long learning experience hosted by AinA which includes people who receive services and also direct support staff from around the state. Their voices added to the conversation.

What follows is a combination of ideas and common themes that people expressed when we met. As requested by the people who were a part of the conversations that took place, we also included many direct quotes from attendees, but did not cite their individual names. Additional materials, including meeting notes and sample graphics that people created to help explain the Request for Ideas are attached in an addendum.

Feel free to contact us with additional questions.

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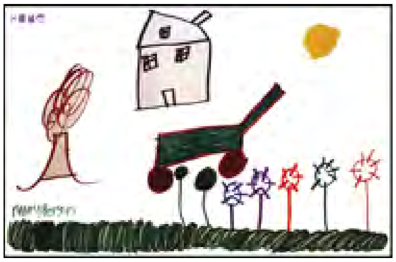

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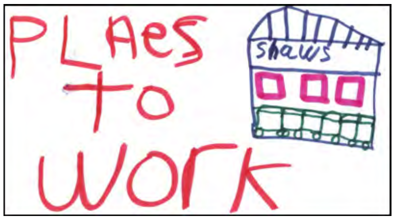
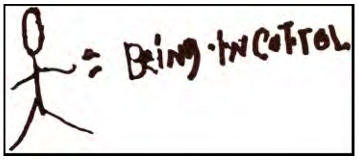


Systems Improvement Area 5: Pay for Performance System for Providers



ADDENDUM

REQUEST FOR IDEAS

Systems Improvement Area 1: Self-Determination

Self-Determination is a philosophy that asserts that people have a right to live where they want to live, stay connected to families and communities of origin, and choose what they want to do, with whom, when, and how they want to do it. Self determination encourages an individualized lifelong planning approach with an emphasis on independence, self-direction, informed choice, and consistent opportunities for reassessment, new choices, and change.

What innovations and changes would you suggest to the current system to actively support and encourage self-determination, maximize natural supports and consumer/ family driven life decision making?

"I am the self in self determination!"

We gathered ideas, key themes and quotes that spoke to Self-Determination into this category. We listed key themes that developed durring our conversations with people in the boxes below. We noted the ideas that spoke to these themes with a lightbulb.

Because Self-Determination is one of the most essential building blocks for any systems change, we believe that most of what you find listed here also applies to many, if not all, of the other System Improvement Areas.

People need to know ALL of their choices. Currently, there is a tendency to only look at the standard set of options (ie: live in an apartment or in a group home). A System that encourages Self-Determination helps people learn to look outside the box and see "what's possible".

If the System wants to promote Self-Determination, it should provide support, information and outreach about the services that are available and "what's possible" in a way that is accessible and convenient.

💡 A "Resource Network" can help make this happen. The network could include a variety of material in as many formats as possible. Information could be made available on line, and also have a physical address at advocacy organizations, state offices and provider agencies. Information is power! The more, the better!

People need to UNDERSTAND their choices. A System that encourages Self-Determination helps people who receive services and their families to do this. Not everyone can read or write. Not everyone can process complex ideas or comprehend "big words", but this doesn't mean they can't be in control of their own lives. Whatever System changes occur, people need to know what they are and what they mean. Whatever options become available, people need to understand them.

💡 Materials should be created in a variety of formats. The System could support the creation of this information and helps ensure that it is available in language that is simple and accessible.

People need to learn how to make decisions. Many individuals who have a developmental disability have never had the opportunity to make basic life decisions. If the System wants to encourage self-determination, it needs to help people learn decision-making skills.

Collect, develop and/or adapt materials and information about how to make decisions. Get this information out and into the hands of people who need it in as many ways as possible! Remember to include the experiences of people who already made these decisions. People can learn a lot from their peers!

People need to be involved in the process. This idea is best captured in the phrase used in the Self-Advocacy movement, “nothing about me without me!”

Systems change initiatives and activities should include people who have a DD and their families.

* Include people in meetings and communications.

* Make sure that these are accessible physically and in terms of materials shared.

* Take into account the needs of the people the meetings are ultimately all about.

* Remember simple things like the length of the meeting and taking breaks.

* Remember that while many people who work in the field are paid to be in the room, people in the system and their families are not. Many need to use valuable staff hours to attend, take time out of work and also pay for transportation to get there. Consider offering a stipend to help support individuals and family members so that they can be at the table.

Information should be unbiased. Right now, the main place that people go to find out about services is the State. People may also be referred to provider agencies to find out more. While both may provide necessary information about services, it can be seen as biased.

Support the creation of a non-biased third party source of information. It’s mission and function should be to share resources about what’s possible. It should NOT provide any direct funding or services. Such an entity would be able to get people the objective information that they need, which could also be made available thru the resource libraries mentioned above.

Access to information needs to START EARLY! Young people who have a developmental disability also need to start learning real life decision making skills as a part of their general education.

Start Self-Advocacy groups for young people to join, and offer a variety learning opportunities for them while they are still in high school. Rhode Island currently has a network of Self-Advocacy groups around the state. Members of these groups have noted on more than one occasion that they would be willing to mention and help support young adults to start SA groups in local schools.

In a System that encourages Self-Determination, access to information STARTS EARLY! Families who have children with developmental disabilities should start learning about what’s possible and making plans while their kids are still in school.

* Families should be connected with the above mentioned resource libraries. Families should also be connected with support groups so that networking can start early.

* The Rhode Island Parent Information Network (RIPIN) could help disseminate information to familes while their children are still in the school system.

* Make person-centered planning tools available for young people and their families tp give them a road map for decision making

* Work with the Department of Education so that there is a uniform set of standards for schools to follow.

For Self-Determination to work, people who have a developmental disability should “feel good” about themselves. Society should view them as equal members with value. At present, society doesn’t tend to promote a positive image around disabilities. People are still viewed as being “needy”, more than seen as a resource. Most people who have a developmental disability also still lead lives that are segregated in many ways. People are valuable! A System that encourages Self-Determination supports ways to spread this message.

Personal stories can be be collected and shared. People/families with an area of “life expertise” to share need opportunities to tell their story (and have it recorded). People who are looking for what’s possible should be able to access these stories. Stories should be in a variety of formats including video, audio, photo and written word. The “Story Corp” project is an example of the power of the individual story (http://www.storycorps.net).

Everyone is an expert about something! Being asked to share your expertise encourages self-esteem, which is vital if a person is going to be in control of their own life. A System that encourages Self-Determination will view the people it supports as a resource and help them share their experiences so that others can learn and grow.

Individual Choices should be respected. If an individual and their family make an educated, responsible decision that WORKS FOR THEM, but it is not part of the “norm”, or is different from the way things usually work, this should be OK! People should always feel like they really ARE the “self” in Self-Determination!

Develop and conduct training for direct support staff and agencies. Provide learning opportunities to teach those who work in the service system about Self-Determination. Whenever possible, individuals who receive services and their families should be a part of these trainings and the main teachers.

Self-Determination does NOT mean that people who have disabilities should be treated special or different. It means equality. People should be an integral part of their community and contributing members of society. Providing “staff hours” isn’t always the most effective or efficient way to make this happen. A System that encourages Self-Determination sustains and encourage “natural supports”. Currently many rules, regulations, and/or perceptions of what is and isn’t allowed prevent a lot of natural support from taking place.

Examine and work to change existing rules and regulations that get in the way of people living a natural/equal life. A few examples of these might include allowing/ supporting things such as:

* Make reimbursement stipends available to family members who provide rides for relatives who are a part of the DD system and living at home. Consider what other expenses could be reimbursed, such as internet services fees that pay to get connected.

* Allow individuals flexibility with their funding. Rather than paying a staff person to drive them to the grocery store, they could use a delivery service such as Peapod (thru Stop and Shop). Home deliveries cost $5.00. People may need help making a list and placing an order, but valuable staff hours could be saved.

* Another example of flexibility with funding: If I am a person in the DD system and I want to attend a concert or take a class, I could buy a ticket or cover the course fees for a friend or neighbor, in exchange for a ride and/or support while attending the event.

WHAT PEOPLE ARE SAYING: *“QUOTABLE QUOTES”*

If you want something, then that’s what YOU want. It’s the choice for you. Someone else may want something different. That’s THEIR choice.

Respect my choice!

Being in control means being bossy about your own life ... because it IS your life!

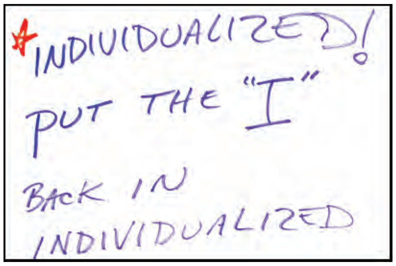
Maybe they do need to make some cuts, but I still want to be the one to decide about the cuts that affect ME. If something needs to be cut, I want to decide what it will be. I want that choice.

Being in control means being able to ask questions. It doesn’t mean you have to know all the answers.

Being in control means being able to plan how, where and who I want to spend my time with.

Here’s my recipe for ME:

- *My Skills (things I am good at, things I know how to do)*
- *Things I need some help with*
- *Lots of information to help me learn (that I can understand)*
- *Support from my staff*
- *Support from family, friends and community*



*INDIVIDUALIZED!
PUT THE “I”
BACK IN
INDIVIDUALIZED

Independence doesn’t mean doing everything by myself. It means doing what I can and knowing when to ask for help (and being able to get the help I need).

Being in control still means I need to be safe.
I may want to try more things and some things may be risky.
I need to understand what all the risks are.

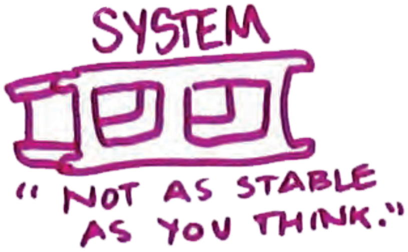
How do other people make decisions? We can learn from each other!

I don’t want someone to make big decisions for me.
I want to learn how to make my own.

It feels GOOD when people know who I am! When I go to the store,
they know me and I don’t need to show my ID when I write a check.

When I go to a restaurant, they know me and they know how I like my coffee.

Who is “pulling the strings in your life”? Are you controlling them,
or is someone else moving them for you?



"The System needs to be more flexible.
If the thing I was trying to do wasn't attached to the System,
it wouldn't matter! The System gets in my way."

SHARE RIDES: Maybe agencies have to change some of their policies.
Why can't staff from a different agency give me a ride if they're going my way?
If they support my friend and they are driving them, and
my friend wants to give me a ride,the staff should be able to give me one.

If you're going the same place I'm going, why can't I just pick you up and bring you?

If we're going to the same place, let's go together!

SHARE RESOURCES: Staff are tied to one agency and the people they support too much.
How can we share staff hours?

"I don't mind sharing my staff hours, but I don't want to be told WHO I need to share them with.
I still want to be able to chose and be in control of my life."

SHARE RESOURCES: Can we share with others? "If my neighbor is going to the grocery store,
how can I pay them money for gas and go with them, instead of using staff hours and mileage?"

I live in my own apartment, but I'm connected with a group home nearby. They pick me up for rides on the way to the store and other places.

If a friend wants to take an art class that I'm planning to take, could I pay for their tuition and let them drive me to class and help me while I'm there ... instead of paying staff hours and mileage?

SHARE RESOURCES: We all have something to share. People are great resources!

If I know how to do something, let me show you how to do it. Why does it need to be a "staff job"? I take the bus, come with me!

I need to be able to ask someone who's done it before; someone who's already made (or not made) the decision I'm trying to make. It would be good to be able to find some of those people and talk to them.

FIND OUT ABOUT OTHER RESOURCES:

More people could apply for Food Stamps. More people are eligible and everyone penny helps!

More people should have bus passes and learn how to take the bus
(people who know how to take it now can teach others!)

MAKE THINGS EASY TO UNDERSTAND

Use simple language (remember: People who can read big words can read small words, too.)

Some Big Words: Sometimes some of the technical stuff has to be in big words. I don't need to have all of those details. When I go to my doctors, I don't need to understand all the medical stuff. I just need to know what's going on and that no one will do something to me without my permission.

Different Formats:
photos - of people, places, etc
video - stories from people, video lessons,
audio - so people can hear what's written
pictures - drawings that people make to share ideas
clip art - computer pictures to share ideas
symbols - create some common symbols to use to help explain pieces of the system and different choices? If everyone uses the same symbols, it could help people understand
artwork - people have lots of different ways to express themselves and share ideas

Available to All! The information needs to be available in lots of places - for EVERYONE (not just people connected with "the System").

** Put it on the internet*
** Put it in public libraries*
** Put in agency libraries*
** Put it in Resource Libraries*
** SHARE IT!!!*

Be patient. Change can take time, but DON'T GIVE UP!

SPEAK UP! We need to speak up! We need to vote about what's important t us!

I work, so I'm a taxpayer, too. We need to speak up! If we don't speak up, who will? We need to speak up, but ... who will listen to us? People need to listen!

It will be us who suffer in the end if we don't speak up! This is about our lives!

REQUEST FOR IDEAS

Systems Improvement Area 2: Life Choices Broker

A Life Choices Broker is a personal advisor (objective and non-biased), similar to a financial advisor or a legal advisor, who has the knowledge and expertise necessary to assist a citizen with developmental disabilities to make informed life choices and provide consistent opportunity for reassessment, new choices and change. A Life Choices Broker would need to be specially trained and certified by the State of Rhode Island as a qualified Life Choices Broker. A Life Choices Broker would advise a citizen with developmental disabilities as to their available options for housing, employment, supports to daily living, personal supports, and community involvement and to act as a liaison to the individual's fiscal intermediary, as necessary. A Life Choices Broker must be impartial and not have a conflicting role in relationship to the citizen with developmental disabilities s/he is advising.

Request for Ideas

1) How can we best create capacity to ensure that citizens make informed choices?

As described in the System Improvement Area 1: Self-Determination, we believe that ensuring that individuals/families are able to make informed choices is critical.

Individuals will be afforded opportunities to learn about decision-making and life choices. They have the same freedom that others have to make mistakes and/or to change their mind. As described in our SD response, all materials developed to support and encourage choice will be available in a variety of formats that are accessible and easy to understand.

2) What should be the specific functions of the Life Choices Broker?

The LCB doesn't need to be "just one person". It could be seen more as a service that is provided to people who have a developmental disability which is based on the individual need.

LCBs also don't need to be "professionals". People and family members who have life experiences of their own to draw from, who also have a developmental disability, could fill this role.

Create a LCB Bank. Fill the "bank" with lots of people who are willing to fulfill the role of LCB in some capacity. Individuals/families who are looking for help in a certain area can access the LCB Bank as a resource.

Good Life Choice Brokers:

Listen

Are life focused

Build relationships

Answer questions, or know where to go for answers

Are effective – they should work themselves out of a job and step back when support is in place

They should specialize. This does not need to be their main job.

Have a strong sense of social justice

Are committed to understanding self determination, freedom and civil rights

Have the ability to develop close relationships to those who receive support and all those important in the lives of individuals with disabilities

Are clear and concise communicators

Have the courage to take a stand on behalf of the person supported

Have a sense of humor

Can work well despite ambiguity

A Life Choices Broker (LCB) should be able to do what the individual/family requests for support, rather than following a list of regulations about their job function. Flexibility and respect for the person/family as the one who is in charge is key.

WHAT PEOPLE ARE SAYING: *"QUOTABLE QUOTES"*

CONNECTIONS: It helps to have a LOT of connections - not just staff connections or people "in the system".

Connect with:
neighbors
friends of the family
customers and co-workers
people at church (temple, etc)
community clubs and groups
places to volunteer
Students in community classes (art class, cooking, etc)

How can I make a decision about my life if I can't understand the material or information?

You need to believe in yourself 1st. Feel good about who you are and THEN you can speak up for yourself and start to decide what you want in life.

If I don't understand it, I'm not really making a "choice". It's more like a gamble.

Yes, make your own decisions, but know the facts!

We need to get the information AND understand our choices before we can make decisions.

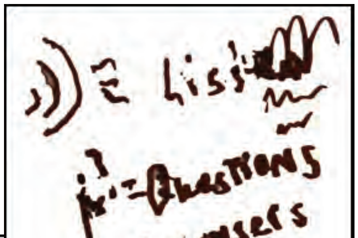
I need information to be able to make choices. I need to know what will happen when I make a choice. What are the consequences?

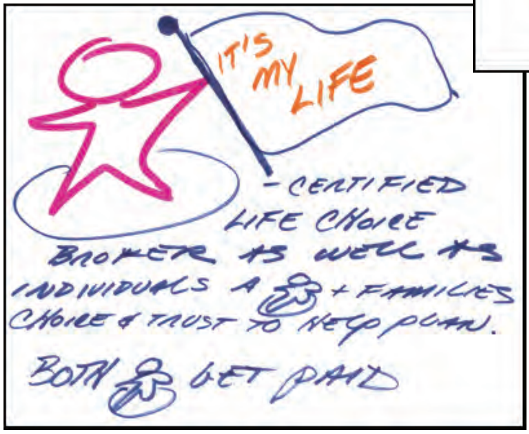
I want staff who will listen to me. Sometimes no one listens to me (not staff or anyone else).

I need to be able to try things before I decide.

I need to be able to make mistakes.

I need to be able to change my mind.





REQUEST FOR IDEAS

Systems Improvement Area 3: Housing Options

"People are looking for choice in terms of their living arrangements. People want to get out on their own…"
~ The PAL Consumer Survey, 2006

Housing and related costs are not covered currently under the federal Medicaid program. SSI stipends are insufficient to pay for the full cost of housing in the Rhode Island marketplace. Group homes owned by the state are now aging, and the state has insufficient funds to maintain the homes. Most of the 24-hour residential supports the state provides rely on full-time paid staff hired by and responsible to someone other than the person with the disability. Increasingly, citizens with developmental disabilities, especially younger and/or more independent citizens, seek and value supports that allow them to hire their own support staff, and live more independently, with family, or with friends, as long as they are able.

Request for Ideas

Housing Options: Living with Your Family and Family Supports

Rhode Island currently provides respite, personal care services, and homemaker services to support families.

1) Are these the right supports?

We believe that respite, Personal Care Attendant (PCA) and homemaker services are critical to support families. However, the way that these supports are labeled has the potential to limit what is possible under state and federal reimbursement.

Review the language and the restrictions of the funding sources to determine what might need to change in order to use the funds that a family and individual are eligible for in the most creative and holistic way in order to insure that the true needs of the individual and family are met.

2) What other supports are needed?

Supports that are in place seem to address the needs. What is lacking seems to be the flexibility to use as needed.

Review the current manner in which Family Supports are provided. Find ways to add flexibility to the System.

3) What can be done differently to encourage and support individuals who would like to continue to live with their family?

One of the greatest challenges that families face when choosing to keep their children/relatives at home is accessing reliable, quality home and community supports. Currently, provider agencies are unable to offer adequate assistance on a consistent enough basis for families to feel that they are “being supported”. Agencies are challenged with providing support to individuals who require both day and residential services because there is no one else. The default position for Providers has historically been that, if all goes well, those folks living at home with their families can count on the support, community access and respite. If staffing issues arise, the support and safety for folks who don’t live with and/or have a family to rely on comes first. Meanwhile, individuals living at home get short-changed and their lives are impacted.

As a result, families have figured out that “placing” their children/relatives who have a developmental disability in a residential support setting (ie: group home or apartment) provides a more predictable and reliable option.

Establish a Family Support Option, whose sole mission and focus would be to help families who want to continue living together are able to do so. This option would provide the services a family needs to make keeping their adult son/daughter/relative at home possible. This would make it possible for families to enjoy quality time when they are not in the care giving-receiving role.

A Family Support Option could also increase the confidence that families in support services. If families felt that they had quality services available, which could be delivered in a reliable and timely fashion, the stress of wondering if they can really count of an evening off or a night away would not drive the demand for more intensive support.

The “Family Support Option” could be part of a Provider where the family has a relationship. It could be a line item in an individual’s budget. Families could direct the funds through a fiscal intermediary.

Housing Options: Supported Living Arrangements

Supported living arrangements are when a family or individual welcomes an individual with developmental disabilities into their home. Or, in reverse, if a citizen with a disability welcomes an individual or a family to live with them in their apartment or home. Rhode Island has relatively few (less than 100) individuals in supported living arrangements.

1) How can Rhode Island assure that every individual currently understands the full range of supportive living options?

The earlier individuals are supported to engage in some form of futures planning, the greater likelihood of success in life. Life Planning helps people begin to think about what life skills they could be working. It also bolsters self-esteem, as the person is able identify, experience and enjoy their success. Life planning helps a person to define their own outcomes, and then shape their understanding of what is possible.

Create more opportunities for people involved in the DD System to learn about Future's Planning. Consider hosting "train the trainer" events to teach these skills to support staff, Life Choices Brokers and anyone who is interested in the process!

Providers, Advocates and those families and individuals with disabilities who have created alternative options should be recruited by the "Resource Network" (as mentioned in the Self-Determination Area) to share their life's journey. What have they struggled with and what successes do they celebrate?

Life experience, especially when it is shared by someone who may be considered a peer, has tremendous value and power! Sharing these stories also affords individuals to make a contribution in their area of expertise….living a life!

2) How do individuals remain aware of their ability to choose more supportive living opportunities now or in the future?

Part of what should be possible through a "Resource Network" is the ability to have a range of stories that speak to individuals in all stages of life's journey. People can learn from each other at any age and in any situation!

Some Providers have rich and touching stories about supporting individuals through the end of their lives. People who have lived with such individuals have also made their personal contribution to those situations. These stories need to be captured and celebrated. The lessons learned need to be passed on.

This is also part of how we bring individuals with disabilities into full membership and contribution to their communities. The concept of "aging in place" is used in many assisted models of care for the elderly. Individuals move into assisted living setting and regardless of the increased need, they are able to stay in their home and supports are provided where they live. We have successfully done this for individuals with disabilities, but there needs to be a heightened awareness of how it happens. Again, if we share our learning, we will cultivate a fertile ground for individuals ideas of how to make it happen.

Housing Options: Living independently or with friends

Many citizens with developmental disabilities are choosing to live on their own or with a special friend, partner or roommate(s).

1) How can Rhode Island better support persons in independent living situations?

Individuals who are now becoming part of the DD system bring some new challenges to the table. Some come with very significant needs, behavioral and/or medical. Others are more experienced, with higher expectations about being an adult, but are not necessarily as aware of the responsibilities.

Create and support a network of mentors. What we know nationally and in our own communities is that mentors have helped shape the future paths for young students and individuals who have been marginalized. We believe that investing time with those students in transition at an earlier age will afford us the opportunity to build relationships and to connect individuals who have interesting life stories to share. That is the beginning of a network of people in the community!

2) What do citizens with developmental disabilities need in order to live as independently as possible?

We think one of the best ways to answer this question is to ask the people themselves, so that’s what we did. Here are some of the key ingredients that Rhode Islanders who have a developmental disability had to share:

We want support staff who REALLY listen to us. Staff training should include good listening skills. People who receive services can help teach staff how to listen as a part of a staff training curriculum.

We want to be in charge of our support. People need support that they get to direct, as independently as possible. Resources on how to hire, supervise and evaluate staff that is accessible and easy to understand would help people who have a DD to do this.

We want to control our front door. People want to carry the key to their home, to know who else has a key, and to be able to say “no” if they don’t want someone to have one.

We want to choose where we live. People DO know they need to live within their means, but they still want to decide where that will be.

We want to pick the people we live with. People want to decide who lives with them. They don't want to just fill the empty bed in their home with another individual that an agency supports. They want to pick their roommates because they are the ones who will have to live with them.

We want our own staff. Those individuals who choose to work through an agency would like to have their own support. They don't want staffs who have been pulled from another "program' because a shift needs to be covered. They want staffs who know them (and who they know!).

We want "whole life support". People want more attention paid to their "whole lives". Life doesn't happen in segments. People don't want "day stuff", with staff who only know their day life, and separate home support, with staff who only know their home life. They want a holistic approach to their support.

We want "the System" to get out of the way! People are more than willing to be flexible. If some support can happen naturally, people want to let it happen. The answer to every need that arises is not always "more staff". Sometimes the answer is simply a flexible System that will support the best solution for the situation.

We want "rollover hours". A system that encourages Self-Determination would find a way for people to use their hours when they want and need them, with the flexibility to spread those hours over the course of a fiscal year.

We want to choose where we live. People DO know they need to live within their means, but they still want to decide where that will be.

The Support Agreement has the potential to be a valuable guide around expectations and responsibilities for both the individual, family and the provider Agency.

There should be some significant investment of time and conversation with individuals and their families with regard to the Support Agreement..

WHAT PEOPLE ARE SAYING: *“QUOTABLE QUOTES”*

Please DON’T BUILD MINI INSTITUTIONS! I may be ok with a “house mate”, but I don’t want a ROOMMATE. I need some of my own space. I at least need my OWN ROOM!

It takes a long time to get to live in your dream home and your dreams may change.

I’m an adult. I’ve tried living in different places.
Now I know what I want and it’s MY OWN SPACE.
It not because I dislike my house mate.
I just need to have space that’s only mine.

I moved out of my parents house but I didn’t like it, so I moved back home.

People need to be able to change their mind.

A “Home” doesn’t have to be a house. A home is a place I live where I am comfortable, safe and I feel like I can do what I want.

There aren’t enough safe and affordable places for people to live. The place I live now has gotten very scarey to live in with a lot of crime around me. I applied to other section 8 places to move, but they have long waiting lists.

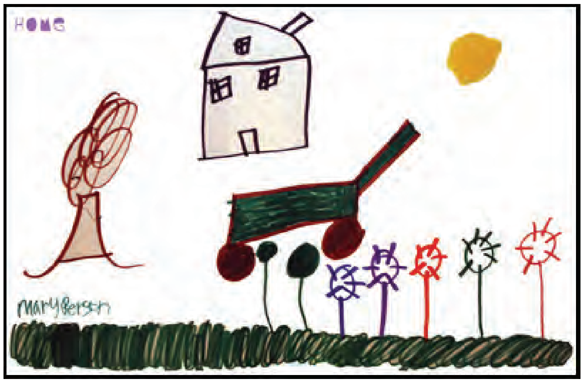
Housing is important. We don’t want to be homeless! There just aren’t enough places that people can afford to live.

There aren’t enough accessible places for people to live, either.

I don’t need to own my home. I don’t even WANT to own my home. But I do want it to be “mine”.

My OWN home means:

** I can decorate it the way I want.*
** I have my own key.*
** I know who else has keys to my house.*
** No one can have a key if I don’t want them to.*
** I have privacy.*
** I can control things IN my space and still not own it.*
** I feel safe.*
** I can invite guests over when I want.*
** I can make a mess and clean it when I want.*
** I can be cluttered.*
** I can have a date over.*



I used to live at Ladd. Now I have my won apartment and I’m proud of my home. I like taking care of my home. I want to take care of it!

Having a home means having the responsibilities that go with it: paying bills, cooperating with house mates, keeping things clean, etc.

It’s about TEAMWORK. My staff may work for me, but we are a team (and I’m the captain!)

I want staff to like me for who I am and not try to change me. I want them to support ME in MY life.

EMPOWER STAFF: Sometimes my staff says they want to do something that I want, but they don’t think they can. Maybe there are too many rules that stop good staff from helping us.

Staff need to feel like it’s ok to make some decisions if I ask them to. They need to be able to answer to ME as the person in charge.

People don’t always need “staff”

Good help is there for me when I need them, but also lets me try for myself. I may move more slowly, but I don’t always need help.

I can take the bus some places. Sometimes staff brings me, but other times I take the bus.

Good help doesn’t always have to come from staff. Sometimes people just help each other. That is really GOOD help because no one gets paid for it!
Good help isn’t “all or nothing”. Sometimes I have to be flexible, too. May want things a certain way, but there may be some good reasons that I can’t do them that way. But good help will try and explain this to me. They won’t just say “no”.

Good help helps me learn about all my choices.

Good help helps me get to the places I need to be and supports me while I’m there if needed. It’s not just a ride to the doctor’s. It’s help planning the appointment, telling the doctor what’s going on, understanding what the doctor says and following any instructions the doctor gives me.
Good help helps me do the things that are on MY LIST (not theirs). They come with me to grocery shop, instead of me going with them.

Good help asks me what I really mean if they don’t understand me.

Good help:

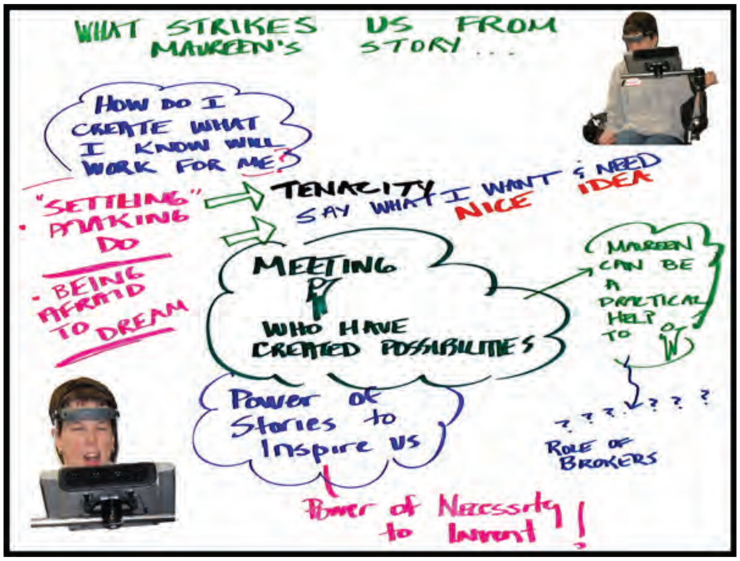
** Teaches me*
** Supports me to be more independent*
** Helps me learn to rely more on myself and not as much on them*
** Follows my schedule, no theirs.*
** Helps me make community connections so I don't just rely on them or on "the system".*
** Helps me decide how to budget.*
** Are loyal to me. They know they work for ME first.*
** Respects me and is honest.*
** Asks ME what I need.*
** Gives ME information and keeps ME informed so that I can MAKE MY OWN DECISIONS.*
** Helps me express what I mean if I can't make my point the way I want.*

THINK OUTSIDE THE "STAFF BOX": Find local places near where you live and WALK to some places that staff usually drive you to.

THINK OUTSIDE THE "STAFF BOX": Ask someone from church to pick you up. Connect with the community more and share what you can.

THINK OUTSIDE THE "STAFF BOX": Have your groceries delivered from Peapod! It only costs $5. It saves staff hours and mileage. Plus, going to the grocery store isn't the most important thing on my "to do list". I have other things to do with my support hours.

Life is short and you only live once. Everyone should be able to grab it and try it! Part of life is being able to make mistakes. Please let me try something first before you jump in to help. Good support means giving me a chance to see what I can do. I may not need as much help as you think! I may not do it your way, but I can still do it!



REQUEST FOR IDEAS

Systems Improvement Area 4: Employment

"People see jobs as an opportunity to make money which affords them more choices and control in their lives to do the things they want to do to have a good life…"
~ The PAL Consumer Survey, 2006

Employment is an empowering life opportunity. People with disabilities have the highest unemployment rate of any other minority group in the country and in our state. Most individuals with developmental disabilities have the ability but not the opportunity to have meaningful employment within the community. The Rhode Island community in many instances needs to be informed, challenged and engaged in offering employment to citizens with developmental disabilities. Currently there are insufficient opportunities in Rhode Island for both supported (place, train and support) or independent (train and place) employment in community workplaces. The percentage of citizens with developmental disabilities working in Rhode Island approximates 15%. In other parts of the country over 60% of the citizens with developmental disabilities are working. If we strive for inclusion and equitable life choices for persons with developmental disabilities, employment must be a renewed priority in Rhode Island.

Request for Ideas

1) How can we create, cultivate and promote positive opportunities for employment in community settings?

Employment information about Rhode Islanders who have a DD would be useful. How many people who have a DD are working in their community now? What kinds of jobs are people doing? How many hours do people work? How much money do they make? Have people moved up along a career path? What types of supported employment services are available? How can people access those services?

Support the creation of a 3rd party entity whose role is to both gather data and also act as a supported employment resource for Provider agencies, businesses and individuals.

This entity could be modeled after the structure of the RI Disability Vote Project (but without the paid membership requirement). A coordinator from the RIDVP visits its member agencies to find out which individuals, staff members and other affiliates are registered to vote and actively voting. The RIDVP helps agency to increase these numbers, and also provides resources about voting and election issues.

Creating a similar model, with a focus on supported employment, could help increase the number of individuals with a DD that are working in the community.

Define what a “real job” is. Many people who have a DD spend their days volunteering in a variety of community settings. Animal Shelters, Nursing Homes and programs such as Meals on Wheels and the RI Community Food Bank rely on these individuals. During our conversations about this System Improvement Area, people who are volunteers made it clear that they are proud of what they do and feel that this “work” is important. When we talk about employment and “real jobs”, we should see beyond the paycheck.

Connect with the Volunteer Center of RI and other organizations to find ways to promote the positive value of being a volunteer.

Connect with places that need volunteers. Look for opportunities for people who have a DD to become involved.

Individuals with a DD who are seeking community employment need more information about what’s possible. People need to learn basic job skills. They also need to figure out what type of work they would like to do. Not everyone who has a DD wants to bag groceries, wash dishes or push shopping carts. People need to know what their marketable skills are, how they can learn more skills, what their employment options are, and what they need to do to get the job that they really want.

Connect people who have a DD with employment resources in the community such as Network RI.

Create and support tools that people who have a DD can use to identify their individual talents and gifts and build these into a resume of marketable job skills.

Outreach to students while they are still in high school. Teach Guidance Counselors how to help young people who have a DD pick a real career path.

Collaborate with the Department of Education so that job skills training and career path development can begin in high school and will carry on into a person’s adult life.

Support a network of Mentors so that those who have jobs now can support those who are seeking employment.

A person could opt to have a “Life Coach”.

A Life Coach benefits both the employee and employer by:
Helping an individual increase their overall contribution to the workplace
Helping an individual develop an expanding set of interpersonal relationships at work
Helping employers recognize a person’s contributions to the workplace

2) What are appropriate expectations of persons with developmental disabilities to work and/or otherwise contribute to the community?

People who have a DD don't want to be treated "special" or different. They should have the same expectations as anybody else.

Promote and support equality. Help people who have a Developmental Disabilty learn to appreciate who they are, and all of the ways that the can contribute to their community.

It's hard to have expectations if you don't know what your options are.

Systems Improvement in this area should provide training and resources for people who have a DD. People need to know what having a job and/or contributing to society means. The network of mentors mentioned above would be an excellent tool for people to learn about the employment/ community involvement experience.

People should EXPECT that they will keep getting the supports they need to be able to be contributing members of society once they obtain a job ... that makes them a contributing member of society! People who have a DD are currently limited in the amount of money that they can earn. Depending a person's circumstances, they will have to pay for their support hours after they earn a certain amount. The numbers do not encourage people to work. "Why work if I will have to pay all of my money toward support hours?"

Make changes in regulations and/or public laws so that people who have a DD won't be penalized by the loss of support hours because they are working.

3) How do we identify jobs and support employers, as they employ citizens with developmental disabilities?

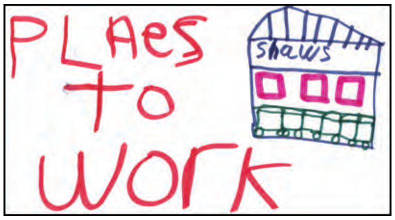
Increasing employment rates in the community for people who have a DD requires education and awareness. Potential employers could benefit from disability awareness experiences which promote the value and contributions that people who happen to have a DD can bring to the table. These trainings could also help businesses interact with and meet the needs of customers who have a DD.

- Develop and share disability awareness training for businesses and in other community settings. These would be especially effective if people who have a DD are the ones conducting the teaching.
- Create a RI Job Community Bulletin board that is networked with stakeholders in the DD system (individuals/families, provider agencies, advocacy organizations, MHRH, etc. Link with and add to similar bulletin boards that may already exist. Make the site simple and easy to use. Offer free listings to both employers and those seeking jobs. Add a variety of ways to search the site so that people can match their skills to jobs which require them.
- Offer a free employment consultation to local businesses. A consultant would meet with a local business to evaluate their situation and help them figure out ways that they can employ people who have a DD. This consultant could also help businesses understand any possible tax or other incentives for that might gained by hiring a person who has a DD.
- Create more tax or business incentives to businesses who hire people who have a DD.

WHAT PEOPLE ARE SAYING: *“QUOTABLE QUOTES”*

It may be a volunteer job, but it’s still MY JOB. I’m proud of what I do. People like me there. It feels good.

What I do for work needs to be meaningful to me.



Just because I don’t get paid doesn’t mean it’s not important.

People need to like what they do.

I have a job. I get paid real money. I want to keep my job!

Having a job makes me feel GOOD about me!

I don’t want to work if it means I will lose my benefits.

I can only find seasonal jobs. I would like to work all year.

I felt amazingly glad to know that people liked the work I was doing.

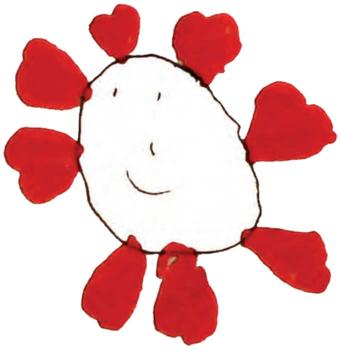
It would be nice to work more than just on Saturdays.

I need my job and my staff helps me get to work. How can I keep my job without my staff helping me?

It’s good to have real work ... and to get paid real money.

I want to work so I can be a part of society - just like everyone else.

Everyone has something that they can do (and share!)
I paint
I sew
I recycle
I shred paper
I greet people with a smile



REQUEST FOR IDEAS

Systems Improvement Area 5: Pay for Performance System for Providers

“Pay for performance” is the concept of providing enhanced payment to providers who contract to work toward and accomplish the goals that the state will set out for an innovative service system. For example, the state is considering paying providers incentives to actively work to identify and offer appropriate SLA placements to individuals currently in group homes.

Pay for Performance contracts with providers would:

Require submission of timely and accurate data
Assure access, quality, and safety of services and supports
Provide incentives to promote and encourage innovation and change to meet the needs and choice of individuals
Provide financial incentives to reward successful client outcomes
Specify quality of life measures or successful client outcome measures with clear accountability
Develop and report performance measures that would regularly be made available to citizens with developmental disabilities and their families, Life Choices Brokers and advocates.
Maximize investment of resources into direct services and supports.

1) What administrative reforms are necessary to assure the statewide system of services and supports is simply understood, easy to access, coordinated, running efficiently, keeping overhead down, keeping quality up, and is consumer satisfaction focused and friendly?

In order to increase creative ways to provide support to individuals, there needs to be opportunities for “trial and demonstration”. Honest conversations about risk and responsibilities need to occur in order for people who have a DD and their families to want to buy-in for such activities.

People should be allowed to make mistakes without penalties. If an individual who receives services wants to attempt something new through their support plan, they should be able to do so without the fear that they will lose support dollars if their trial is unsuccessful.

The System may need to waive some of the regulations that get in the way of being flexible and responsive.

People don’t want their lives to become another number on a someone’s spreadsheet.

As Pay for Performance ideas are evaluated, remember that quality cannot always be measured. Lives that are filled with quality moments cannot always be measured in tangible (reimbursable) ways, but they are beyond monetary value.

2) How can the service and support system be more consumer-driven and accountable?

Ask people if they are getting what they want and give them the tools and skills needed to make an informed response.

Provide individuals and families with the tools listed throughout this RFI to empower them to learn how to speak-up, make decisions and be the person in charge.

Support Self-Advocacy. Self-Advocacy is an international movement in which people who have a DD organize and work together to empower each other to speak up about issues that are important in their lives. Rhode Island currently has a network of SA groups around the state, which Advocates in Action helps coordinate. Most of the groups rely on some support from agencies, which has the potential to create conflicts of interest. Support that comes with “no strings attached” would help promote autonomy in the SA movement.

As mentioned in previous sections, a system that is consumer-driven and accountable should invite and include people who have a DD and families at the table.

Remember that the people being served are the reason that the System exists. Make accommodations that will help individuals to be active participants when they come to the table. Listen to what they have to say and help put their ideas about their lives into action.

Build real life circles of support that think outside of and beyond the “paid support” category. Real life circles encourage natural supports as they connect people with their community.

3) How can support and financing models be designed to be progressive, affordable and sustainable?

Services need to be accessible and flexible. They should match a person’s life circumstances, rather than following a prescribed written plan throughout a fiscal year.

There is a longstanding fear on the part of families and providers that if you “don’t ask for it up front” you might never get the “wiggle room” you need to keep quality and safety in the forefront. If individuals and Providers know that life changes can trigger a change in funding without delay, the current need build into the base dollars for potential changes would not be necessary.

The DDD could simplify access to services and make them more flexible by re-writing some rules and regulations in this area. Make adjustments so that services can be stopped and restarted when necessary without a prolonged period of time.

Make adjustments so that support dollars are available for use as needed, based on changing circumstances. For example: if my job is going well, the dollars in my job coach line could be used to help me with my budgeting or to help me get out more in the evening.

WHAT PEOPLE ARE SAYING: *“QUOTABLE QUOTES”*

Making choices takes planning.

*Support our “natural supports”! Maybe we can give more support to families -
like a gas stipend to help me get places I need to go?
It doesn’t have to be a “paycheck”.
Maybe it can be a stipend for gas or groceries or other bills?*

*COMMUNICATION: Everyone needs to share information better. There are a lot of ideas out there about ways to do thing, about meetings, about different things people do with their lives and about what’s going on.
We need to use lots of different tools to share the information. The information needs to be in ways that everyone can understand. Just because I don’t read, or don’t read big words, doesn’t mean I don’t want to know what’s going on.*

*We should share information in ways that aren’t just in our “circle” -
not just between agencies, but all around Rhode Island (and beyond!).*

*Ways to share information:
The Internet and Email: It would be GREAT if there were
lots of ways for people/families/staff to be able to get on line*

Public TV: People can even make their own cable TV shows

Radio (talk shows?)

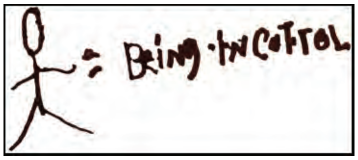
Newsletters

The Newspaper: ie: “What’s Happening” section and local papers, too

Fax Tree: send out news about important events by fax (stamps cost too much!)

Community Bulletin Boards

Public Meetings to share and learn



People need good staff to STAY! What can we do to keep the good staff people longer?

*Good help is hard to find – and HARD TO KEEP!
Whenever I get someone really good, they don’t stay very long.*