

Fostering Social Inclusion and Community Engagement

“.....when you say friends and what [do] they mean to you, I owe a lot of things to my friends and coworkers because they are the ones who gave me the push to go live on my own in my very first apartment...” (Self advocate, North East)

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November 2016



Executive Summary

Background

The Massachusetts Department of Developmental Services (DDS) has undertaken a series of efforts to encourage friendships and community inclusion among the people they support. Currently DDS is developing a formal policy on social inclusion. Regulations, policies and practices may be obstacles to promoting social integration and the kind of relationships that DDS would hope to see as a part of people's everyday lives. Better understanding of people's experiences with making friends, having relationships, being involved in the community, identifying what is working well, and what may get in the way, is paramount to crafting a social inclusion policy.

Methods

DDS requested that the Center of Developmental Disabilities Evaluation and Research (CDDER) investigate, through a series of focus groups, thoughts on social inclusion in the community and recommendations for improving a person's involvement with their friends and neighbors. Ten focus groups were held across the state that included self advocates, families, direct support professionals, group home managers, participants in Creating our Common Wealth, DDS service coordinators, DDS Human Rights Staff, DDS Quality management staff, and DDS area directors. In addition, CDDER attended a Direct Support Professional Certification Class at North Shore Community College. Four interviews were conducted, three with executive level staff at provider agencies and one self advocate.

Themes

Themes emerging from the analysis included: Friendship: what does it mean to have a friend, and what are the benefits of having friends; the Impact of Staff and the important role they play in social inclusion; Balancing Risk, how do we provide reasonable safeguards yet foster inclusion; Role of Regulations and what are the real versus perceived regulation around National Background checks, permission need to participate in activities, staff boundaries and rules on medication administration; eliminating Segregated activities but still Valuing Relationships with others with disability; Funding provided to appropriate programs and trainings that foster social inclusion; identifying and supporting the Transportation needs of people with intellectual and developmental disability (IDD); and other challenges people face around negative social experiences.

Approaches to Inclusion: What Works

Participants reported a number of successful programs and policies that work to promote social inclusion. Some of these are: employment and volunteerism for self advocates, matching "friends" programs; community and recreational programs; training for staff, families and self advocates; matching staff with similar interests to people with IDD ; community based flexible supports; connecting individuals with common interests; and a provider culture that values integration into the community as part of everyday life. Informal ways that work to involve people with IDD in the community are siblings/relatives including self advocates in their social circles; regular, consistent exposure to the same group or

activity; staff/parent providing social skill coaching; and meeting friends through technology (online).

Recommendations

The following list of recommendations is derived from a series of focus groups and interviews on social inclusion and presented to DDS for consideration. Implementation of any recommendations will be at the discretion of DDS.

Person Centered Policies & Guidelines

1. Ensure any policies implemented are person centered, and that there is a continued emphasis on truly person-centered plans.
2. Explore models to mitigate the restrictions to community participation imposed by staffing models.
3. When people request support to make and maintain friends, or become more involved in the community, these plans should be part of the person's ISP, as appropriate
4. Work with shared living providers to ensure that appropriate space is given for the exploration and pursuit of people's own interests.

Invest in Staff Development & Support creativity with support resources

1. Develop a culture that values the staff role as more than a caregiver.
2. Provide staff training on social skills and creative thinking skills on inclusion and decision making. Train staff on their local community and how to engage with it as needed.
3. Explore alternative fiscal and staffing models that address risk but also provide more flexibility to support the pursuit of individual interests.
4. Explore ways to engage with volunteers and other community groups to work around limitations imposed by staffing ratios.

Share the Risk

1. Additional resources about strategies to address risk may be helpful for providers and families. There are real and valid concerns about risks, but at times these concerns can lead to overly limited life experiences.
2. Support the building of relationships between providers and families to help all stakeholders to work together in sharing risk and minimizing blame in supporting people with IDD to participate in the community fully.
3. Share stories about positive outcomes and successful strategies to address risk. Use these to show people who may be fearful what is possible.

Clarify Regulations

1. Better define and communicate the rules on relationships (boundaries) with staff.
2. Provide additional clarifying guidance on medication administration rules, including who can give medications (must it always be MAP certified staff?) and how much flexibility a provider may have in when a medication is administered.
3. Educate providers on specific roles that require National Background checks.

4. Clarify new License & Certification Guidelines. Providers expressed confusion about whether the new guidelines around social inclusion measures be considered as important as other guidelines, and whether there will be consequences for not meeting them.
5. Clearly define what DDS means by Social Inclusion and how that will be measured. Providers are fearful that any new policy in this area may mean more rules and regulations, and more reporting.
6. Discourage blanket rules that restrict people's rights to have guests in their homes, communicate with others, or have intimate relationships.

Segregation and Devalued Friendships

1. Increase opportunities for people with IDD to participate in Unified Sports in addition to sporting events that are only for people with disabilities.
2. Increase access to community-based flexible supports
3. Increase community support; establish relationships with the community so that they see it as their role to welcome people with disabilities.

Funding

1. If additional funding is provided to agencies, ensure it is targeted at appropriate training, finding ways to maintain staff, and increase pay (as described above).
2. Ensure certification indicators regarding social inclusion are included and valued in the evaluation process
3. Explore strategies to address limitations imposed by staff wages and staff ratios/availability, including possibilities for use of non-staff and other community resources to support social activities.
4. Explore options to direct funds toward items that support inclusion such as vehicles, technology (tablets) or recreational activities.

Transportation

1. By working in partnership with the MBTA, DDS may be able to help mitigate some of the service eligibility approval challenges faced by people IDD.
2. Consider providing or encouraging provider agencies to provide Travel Training for people with IDD to learn to use public transportation for regular routes on their own.
3. Clarify whether there are any restrictions on the use of ride sharing and other vendors as vehicles for transportation.

Additional Recommendations

1. Embrace Technology: The use of technology is commonplace in arranging everything from dates, to coordinating meet up events for people with similar interests and hobbies. People supported by DDS can benefit from greater access to communication technology.
2. Open communication channels to allow for sharing of information and ideas to address ongoing challenges. Encourage providers to share stories and models of what's working.

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Background

The Massachusetts Department of Developmental Services (DDS) would like to support people with intellectual and developmental disabilities (IDD) to be included in their communities and supported in forming relationships with people regardless of disability. Working towards this mission, DDS has undertaken a series of efforts to encourage friendships and community inclusion among the people they support. Some of these initiatives include The Employment Blueprint, the Campaign for Shared Living, and support of Widening the Circle, among others. After receiving input from stakeholders at the Direct Support Worker Conference and Creating Our Common Wealth events, DDS has focused on understanding best practices to support social inclusion and where factors such as regulations, policies, practices and other environmental factors contribute to limiting social inclusion.

DDS created a steering committee (See Appendix 1) to develop a process to hear from the people they serve and the people that support them about their experiences with making friends, having relationships, and being involved in the community, what is working well, and what may get in the way.

Under an Inter-Agency Service Agreement with DDS, the Center for Developmental Disabilities Evaluation and Research (CDDER) implemented the steering committee's plan. CDDER, based at the Eunice Kennedy Shriver Center at UMass Medical School, provides research, evaluation and training services to enhance the quality of supports and services for people with (IDD). CDDER held a series of focus groups and interviews to determine stakeholder attitudes, perceptions, and positions on building friendships and facilitating social inclusion for themselves and the people they support. The process included a variety of stakeholders who can help shape the DDS policy – voices from individuals, family members, and all levels of provider agency and DDS staff.

This report summarizes the findings from this work, and is submitted to DDS to inform the development of a policy and related guidance on social inclusion.

Methods

A series of ten focus groups were held across the state that included self advocates¹, families, direct support professionals, group home managers, participants in Creating our Common Wealth, DDS service coordinators, DDS Human Rights Staff, DDS Quality management staff, and DDS area directors. In addition, CDDER attended a Direct Support Professional Certification Class at North Shore Community College. Four interviews were conducted, three with executive level staff at provider agencies and one self advocate.

¹ Note: The term “self advocate” is used in this report to refer to someone who has an intellectual or developmental disability.

Additional details on the methods used can be found in Appendix 2.

Themes

Defining Friendship

Each focus group began with a conversation about the meaning of friendship and relationships. The discussion focused on how participants would define friendship: what it means to have a friend, and the benefits of having friends. Regardless of the participant's perspective – whether a self advocate, family member, provider or DDS staff – similar themes were reported relating to the definition of friendship and the benefits to having friends. Participants used terms such as “provides support,” “reciprocal, “by choice,” “someone who is a confidante,” “happens naturally,” and “provides companionship” to define relationships that they would consider to be friendships. Participants described a friend as someone with whom you can share common interests, laughter, and your hopes and dreams as well as your complaints. Each group agreed that it is important to have friends in your life.

Social Circles for People with IDD

While the definition of friendship was similar across the groups, “who” people considered to be friends differed. Experiences and the degree of social isolation varied among the people with IDD; isolation and restrictions were the most extreme for people with more severe intellectual disabilities and for people who did not have others in their lives to support their social skills and inclusion in the community.

People with IDD living independently, in shared living, or with family, often reported staff and parents/family members as their friends. Individuals living in group homes often described other people with disabilities, either in their own group home or another nearby group home, as friends. People with IDD who attended public schools, worked, or whom were involved with community activities such as Best Buddies, were more likely to identify friends without disabilities.

For example, when one self advocate was asked about whether she had someone she considered a friend, she identified her support staff as a friend. While it is positive when true friendships develop beyond a paid staff client relationship, friendships should not be limited to staff, or by staff.

“Me and [L] go to the coffee shop. She does my housecleaning and laundry and shopping. She takes me to my appointment[s].” (Self advocate, West)

Parents, providers and DDS staff reported that people with IDD commonly describe acquaintances as friends. Many participants discussed friendships that started at school, but

did not continue into adult life. After graduation the day to day interactions fade. Likewise, participants discussed friendships made at work often do not extend to after-hours social activities as frequently as they do for people without disabilities.

“A lot of friends he just texts.... and he considers those to be his friends. ... To get together and hang out once a week, or even once a month, not so much.” (Parent, West)

“When he was growing up in the neighborhood, there were kids, usually younger, that he did a lot with. Once they got older, like the guys at the store, they don’t say, “Hey [P], do you want to go out and get a hamburger or somethingIt doesn’t happen.” (Parent, South East)

The home environment affected the sense of social inclusion for people with IDD. Self advocates that live independently (with supports) expressed feelings of isolation and were more likely to identify staff as their only friends. For those living in a group home there were more attempts made to involve them in the community. However, conflict often arose around participation, as there is often not enough staff for individuals to participate in activities on their own.

“In your house, you say majority wins. In a general way, that’s fair. You got your way, but so and so wants to do this. So [when] can we do what the other one wants to do?” (DSP, North East)

In the shared living model people with IDD live in the home of a family other than their own, or another community member, and share in that person’s or family’s activities, events and social life. One self advocate described her experience in shared living as follows:

“... [C]ommunity living was just not for me. I went and I moved in and I’ve been there for six years, and I just love my family. Over Christmas, they give me Christmas stuff. My family comes, her family comes. Knowing I have this, these people ... who are my friends and my family, that are there when I need them. It gives me such relief that they are there. I can go and talk to them whenever I need them. It’s wonderful. It is wonderful...” (Self Advocate, North East)

While the sense of community inclusion increases for people with IDD in shared living models, they reported not always feeling comfortable expressing their own preferences for activities. This challenge was verified by other participants. There is a risk in this model of limiting choices when a person is expected to fully acclimate to a family’s preferences and patterns. In some cases, people with IDD in a shared living environment attended all activities with the family without input of their own. In other cases, families asserted certain rules, such as returning home in the evening by 10pm, which self advocates felt limited their social experiences.

“... [the] shared living provider who is a member of the [X religious] community herself. She has an individual who is not a member of [that] community who lives in her home. The ISP team was celebrating the fact that this person goes to church with her Much of the language that’s spoken there is the language the individual does not speak. And it’s reflecting a culture that’s not the person’s own. And the individual does not really have a choice of not going there. The family ... goes and the person goes along. It was an eye opener when I reviewed the ISP to be something... to be celebrated when, in fact, it’s not giving much thought to [what] the person’s thoughts, needs, and wants might be.” (Area Director, Statewide)

Note: Recommendations presented throughout this report are derived from the series of focus groups and interviews conducted by CDDER on social inclusion. Recommendations are presented to DDS for consideration. Implementation of any recommendations will be at the discretion of DDS.

Person Centered Policies & Guidelines

Recommendations

1: Ensure any policies implemented are person centered, and that there is a continued emphasis on truly person-centered plans.

Note: People with IDD have stronger social connections when they are supported in individualized, creative ways. They experience the most social inclusion through having people in their lives that get to know them and work with them to find and build their interests and form real, reciprocal relationships. These discussions reaffirmed the need for individualized, person-centered support plans and both the mindset and resources to deliver thoughtful, tailored supports.

2: Explore models to mitigate the restrictions to community participation imposed by staffing models.

“Small individual solutions work better, but as we grow and expand, our expectations change, we need systems approaches that support individuals. How do we develop policy and regulation to support that?” (Executive Staff, Metro)

3: When people request support to make and maintain friends, or become more involved in the community, these plans

“[Friendship’s] a matter of trust. I wouldn’t do something that was matched or paid for by the department. I get my supports from the

should be part of the person’s ISP as appropriate.

Caution: Some self advocates specifically stated that they would not want anything listed in their ISPs about forming friendships or community inclusion. When this is the case, the person’s wishes should be respected. Additionally, providers caution against requiring all individuals to have “friendship” goals.

department but not my friendships. It would be a loss of independence -- my independence is lost if I rely on them for friendship.” (Self advocate, Metro)

4: Work with shared living providers to ensure that appropriate space is given for the exploration and pursuit of people’s own interests.

The Impact of Staff

Workforce

Workforce issues related to staff role, cultural differences, high turnover rates, low wages, and union rules were commonly reported. Participants expressed concern at the high expectations on staff who may have limited skills and/or time to foster friendships and social inclusion.

In some cases, staff considered themselves caregivers, and feel they only have time to feed, dress and get the person they support ready for the day. Participants discussed the power of this perceptual difference; a caregiving perspective may lead to less choice, increased limitations and paternalism. Additionally, providers reported that shifts in people requiring paid supports have resulted in people with greater health and behavioral support needs, which can become staff’s primary focus. To ensure staff understand their role in supporting people’s independence, participants reported that some agencies use formal trainings such as Social Role Valorization that identify undesired behaviors, such as speaking to the person with a disability like they are a child, and teach staff how to build up the social status of the person they support.

“We see direct care professionals as caretakers. We need to change the role staff feel responsible to make people safe. That’s not your only job. They’re not willing to experience life. They’re supposed to make sure nothing terrible happens, nothing goes wrong. We need to change the mindset of what a direct care role is. More advocacy. Life coaching. That comes down from the top, you don’t do this, you get in trouble. Why all this documentation? We need this for survey and certification. The focus on survey is more important than friendships.” (Residential Manager, North East/Metro)

While certain staff ratios must be maintained in settings like group homes for the safety of

the people they support, maintaining those ratios can be challenging for managers. The ratios can also limit staff's ability to take one person to an activity at a time. As a result, providers discussed how efforts to foster friendships are more likely to happen only when staffing is stable and everything else in the service environment is going well.

"I love that idea of one person, one place but a lot of times you can't do that because you don't have enough staff. That's why people go out in groups." (Human Rights, West)

Staff may experience difficulty in supporting people to make friendships and engage with the community as they may not be comfortable engaging socially themselves, or may be of a different cultural background and unfamiliar with the communities in which they work. Participants frequently reported a cultural divide between the staff and, not only the people they support, but the communities in which they work. In some cases there are language barriers and in other cases communities are not accepting of the staff themselves. Staff may be shy or it is not a norm of their particular culture to initiate contact or friendship with others in the community.

"We have a culturally diverse staff and their community – what they see their community and their personal life is very different than the community that the individuals want to interact with or have a desire to interact with. I think it's hard for those staff to transition and to help that person get into their community. There's many communit[ies] within a community. (Area Director, Statewide)

Participants reported that, in some cases, staff cite union rules regarding job responsibilities that limit or prohibit their roles in pursuing social inclusion. For example, staff may consider the support of social inclusion outside of their responsibilities. In another example, certain shifts of staff may not be willing to share chores (like the dishes) in exchange for going to an evening community activity. In other cases Direct Support Professionals reported feeling underappreciated, as much is being asked of them for low wages.

"[The providers] need to support their workers as much as they support their clients. It's not giving us health insurance, or going to school, and they only pay us 13 bucks an hour. I take my client out on my own time, and I love him like one of my own... it's unfair and [they] need to treat us as well as the clients. I'm taking him out to socialize" (DSP, North East)

Training

Participants discussed the need for training of staff to develop confidence in their role as a conduit to social and community inclusion. Promoting friendship and community inclusion for people with IDD requires skills in identifying interests and fostering relationships, and knowledge of the local community. In terms of supporting people with IDD to engage with others, participants across multiple groups discussed that staff who are naturally shy or have

low social engagement in their own lives may be less inclined to help people with intellectual IDD explore their own interests and form new relationships. Some providers include training in new hire orientation on the values of friendships, community and social inclusion. But the “how” is often left up to the discretion of the staff.

As a leader of a support service agency describes:

“The role of support staff is to be that bridge to the community. However, it’s one thing to talk with new employees about bringing their own experiences and culture into play, but there are challenges with some support staff. If the staff are new immigrants and they are struggling with English or finding their place in the community that can present a bigger challenge for inclusion.” (Executive Staff, Metro)

While some agencies provide interview-based inventories to help assess a person’s interests, use of these inventories alone was described as insufficient by state and provider agency staff because people with IDD may not understand activities (e.g. Zumba), or may not have ever had an opportunity to observe or try an activity to assess their own interest. Training for staff should address how to assist people with IDD to explore their own interests. Additionally, some providers are using the “mapping” technique, an exercise to identify and locate resources in the community such as activities, programs or clubs that may be of interest to the individuals they support local to the group home

“...I work with 4 individuals who have some pretty significant challenges, and I can think of a gazillion things we can do. [She] would love to join a chorus at a church. We’ve been doing community mapping. What’s in our neighborhood, and what can we start to create. I’ve’ been doing things like reaching out to say is there anyone who is interested in developing that natural unpaid relationship. Just start to get a pool of people to draw from to make connection. ...” (Provider, North East)

Invest in Staff Development & Support creativity with support resources

Recommendations

1: Develop a culture that values the staff role as more than a caregiver. This type of environment may also work to reduce the turnover rates by working to build a culture that values all staff and the people they support.

Illustrative Quote:

“It’s not just the wage. I think the expectation of what we expect our staff to do. If you don’t pass meds, then you don’t have a job there. You have people who have to pass meds, feed, toilet them, laundry, and shower them, and now we tell them we need to take them into the community. How are you going to do that?” (Human Rights Coordinator, West)

2: Provide staff training on social skills and creative thinking skills on inclusion and decision making. Train staff on their local community and how to engage with it as

needed. (ex. Mapping exercise)

3: Explore alternative fiscal and staffing models that address risk but also provide more flexibility to support the pursuit of individual interests.

4. Explore ways to engage with volunteers and other community groups to work around limitations imposed by staffing ratios such as engaging a volunteer to take someone out during day program or a friend trained to provide 1:1 assistance.

Balancing Risk

Concern about risks of exploitation for people with IDD can lead to limitations that increase seclusion. Multiple participants validated the reality of the risk of exploitation for people with IDD when fostering connections with community members. As summarized by a participant from a provider agency: *“part of living, part of engaging in one’s community, there is a certain level of risk”* (Executive Staff, South East). Numerous people with IDD in the focus groups (or children of parent participants) had experienced exploitation by community members in the past. Across participants of all roles, there were stories of community members stealing from people with disabilities as well as exploiting them in other ways through unpaid work or sexually. Families, in particular, discussed their fears about exploitation:

“As a mother of a daughter, you worry about her sexual... and financial exploitation. These are real things. When other parents with children who don’t have some kind of perceptual difference have the audacity to say I’m “Overprotective,” well walk in my shoes, because you don’t want something tragic to happen to your young person.”
(Parent, West)

However, participants suggested that at times these concerns are used as reasons to impose substantial social limitations. Provider agency staff and service coordinators suggested that parents and guardians may impose excessive limitations compared to the person’s abilities due to these fears. For example, parents or guardians may forbid participation in certain community activities and interaction with community members. As an agency leader described:

“Families will come to me and say ‘I will let my family member participate if you can assure me they will be safe.’ I can’t promise that. [We] will do everything in [our] power to mitigate any danger but we can never tell someone that they will always be safe.” (Executive Staff, South East)

Participants expressed the need to have safeguards in place to protect the individuals they

support, but also want the people they support to have a typical life, which includes some level of risk. There needs to be a sense that providers, DDS and families/guardians are supportive of each other when difficult situations arise. The fear can limit the opportunities to explore activities.

“What happens if guardian says no, but individual wants to participate – how do we mitigate it? As long as a person can demonstrate some level of understanding...”
(Executive Staff, South East)

“In a natural relationship. She wants a sexual relationship with someone. We’re [talking] in a group. We can’t do this, DDS is saying we can’t let her spend time with that person. She went and smoked weed with someone last time she went out with him.”
(Residential Manager, North East/Metro)

“There’s all these fears. There’s a lot of fear.” (Residential Support, North East/Metro)

Participants discussed that the fear, or hesitation, of just one part of a person’s support team can have a limiting effect on their life experience. For example, if a support team member has a limited view of the person’s capabilities, their wish to participate, or underestimates the person’s ability to handle certain risks, this view generally results in a limited experience even when it’s not shared by the entire support team. At times, support team members may themselves need to be supported to envision a different experience for a person with IDD, and challenge their own perceptions about what the person can and cannot do.

In almost equal measure, participants shared stories of successful connections, where both the individual and others took the risk to establish a relationship. These included a couple in the neighborhood inviting a son to dinner frequently, and the son reciprocating by bringing food that he got on special at his job; a co-worker inviting an individual over to watch wrestling; a non-verbal individual, who took long walks with a volunteer, found a way to share their interest, and became friends; and a “matched” volunteer maintaining a friendship for more than 20 years with an individual that started out as a ride to church on Sunday, grew to coffee after church, to dinner with family, and then other shared activities like watching football together – even after the volunteer moved from the shared community.

Share the Risk

Recommendations

1: Additional resources about strategies to address risk may be helpful for providers and families. There are real and valid concerns about risks, but at times these concerns can lead to overly limited life experiences. Some stakeholders may need assistance in gaining comfort with addressing these risks and trying different strategies for community engagement.

Illustrative Quote:

“It is hard to make the policy decisions. It is government dollars and no one wants a tragic event. We worry about what happens when we let a person out on their own. It shouldn’t be a barrier, but we need to acknowledge and be open about the risk we are willing to bear and support. Area offices and staff do get it – especially in individual supports or employment. It not impossible to do it – if they are adults we shouldn’t bear all the risk. But it can be scary.” (Executive Staff, Metro)

2: Support the building of relationships between providers and families to help all stakeholders to work together in sharing risk and minimizing blame in supporting people with IDD to participate in the community fully.

“At some level, there’s just risk and we rather just play it safe. It’s easier and safer. I don’t blame anyone for making those decisions. I’d probably say the same thing under those circumstances.” (Program Director, South East)

3. Share stories about positive outcomes and successful strategies to address risk. Use these to show people who may be fearful what is possible.

Regulations: Real Or Perceived

Discussion in the groups also focused on DDS regulations, or what participants perceived to be DDS regulations, that instilled limitations affecting social inclusion and participation as well as friendships. At times, there was confusion around whether a rule was a DDS regulation, a rule created by provider agencies, or whether some practices are really based on rules at all. Participants reported that the regulations are unclear on who requires a criminal background check (National Background Check), when providers and individuals need to ask permission to participate in certain activities (such as extending an individual’s day or attending an activity out of state) and rules on medication administration, to name the most common.

Permissions: Do we need to ask permission?

Throughout these discussions, it was clear that many people with IDD experienced rule-driven lives, including many restrictions on how they interact with others and what they can choose to do. While self advocates talked about not liking these rules and limitations, some discussed following these rules to avoid consequences such as losing a living situation, while others seemed resigned to accepting the rules. For example, in needing to wait for staff

availability to see friends, a self advocate said he would like more access but “It’s ok. It’s ok.” (Self Advocate, North East) Others expressed anger or frustration at restrictions but felt powerless to change them.

Both self advocates and providers expressed concern over the need to ask permission in a variety of circumstances. For self advocates, asking permission was often about intimate relationships, needing to ask permission for a girlfriend to stay over, or to speak or call with a friend or significant other. For providers, the topic of permission centered on the need to know where the people they support are at all times. While the provider is ultimately responsible for the people they support, it can seem paternalistic to require a person to call for permission when social plans spontaneously change (e.g., to go get a coffee with a community member after church).

One self advocate explained:

“If I want to have to have someone overnight, I’d need special permission... I don’t like that rule... I have this one person I truly honestly really could see us possibly sharing that apartment together. [W]e want to see how it’d be overnight. It feels like at my age, you shouldn’t have to have that so called rule. Some people yes, depending on the situation. Me - who is so responsible, who knows how to handle it, would be so careful anyways- I feel that they should give you the chance. If you fail, then you have to ask for permission. It makes it really hard for me to have time with people...” (Self advocate, North East).

“We want people to self direct but have this expectation to know where they are at all times. So if after gardening, the gardener says let’s go out to eat, the person has to call in and let us know where they are. Creates an awkward dynamic the person is an adult but treating them like a baby. We do it because DDS tells us we have too.” (Executive Staff, South East)

“I get frustrated when I try to call [my girlfriend], her house will hang up on me. They won’t ask who is this, they won’t come and get her, I ask “Is she around?” They hang up –boom!” (Self advocate, North East)

In other discussion, provider staff mentioned that there are some rules in place that no one seems to know where they came from or why. There is a sense that “we have always done it this way” and the rules continue without real justification. Some providers reported needing to ask permission from DDS to bring people across state lines to attend a social activity, but others weren’t sure that this was really a regulation.

“... there are some real guidelines. It makes sense of the safety of them or others. There’s the other guidelines that no one knows where they came from...” (Residential Supervisor, North East/Metro)

Medication Administration

Many of the individuals supported have complex medical needs and require medication. Timing of medication may interfere with community outings or natural interactions, as well as staff resources, as there are limited staff certified to administer medication. Alternative options or plans need to be in place for when people want to extend their outing. In this situation, Providers and the people they support must troubleshoot 1) if the individual can administer their own medication, 2) if another person, friend or family, may assist in administering the medications, or 3) if timing of the administration can be altered. All avenues should be explored in order to allow the individual the freedom to participate fully in an activity.

“Health & safety rules can become complicated, and rules around medication. Some need medications at a certain time – often difficult to plan when someone has to “be back at 4pm” for medications. Take away some of that natural aspects of it. (Executive Staff, South East)”

National Background Check - Criminal Offender Record Information (CORI)

Providers expressed confusion on the regulations regarding who needs to undergo a National Background Check (including Criminal Offender Record Information (CORI) and fingerprinting). While staff and volunteers at provider agencies are required to obtain a background check, friends, co-workers and family of staff are not required. However, some providers are erring on the side of caution and limiting self advocates’ interaction with others in the community based on a perceived need to background any person with which they may come in contact. Participants reported that requiring background checks with people encountered in the community creates an uncomfortable dynamic with potential friends balking at the request.

“If it’s a structured volunteer, they have to be CORI’d. I think what’s unclear right now about a friend in the community.” (Area Director, Statewide)

“...new rules on CORI checks for all volunteers... that is something you don’t ask friends to do.” (Executive Staff, South East)

Boundaries

Direct Support Providers, Provider Agency Staff and DDS Staff all mentioned staff boundaries as a concern and a challenge to manage and regulate. The rules in place are to protect both the staff and the people they support. However there are gray areas, and a sense that if strict boundaries are implemented, natural relationships do not occur. In addition, there is confusion about whether the regulations related to friendships between staff and people receiving services are DDS regulations, provider regulations or both. Provider agencies have implemented their own guidelines which results in varying rules

across the industry. These varying rules, including whether staff can spend time with an individual outside of work, can invite an individual into their own home, “friend” an individual on social media, or identify which “friends” require a criminal background check often cause confusion.

Participants reported that while there are rules in place, staff do maintain friendships with the people they support, indicating that it can be difficult to not develop a friendship.

“Many years ago it was accepted that staff would share positive aspects of their personal lives –and their friendships even after employment ended had a positive value. There was a shift and to a professional boundary approach, like a therapist or social worker.... However, there seems to be groundswell of movement back again to that nuanced and fluid approach to relationships with staff and the people they support. It’s a good thing. Want to be sure folks aren’t being exploited, ... [but] a number of employees maintain friendships with people they formally supported” (Executive Staff)

“It’s hard because the rules are telling you - you shouldn’t friends with this person. You’ve known this person for 22 years. To me, it’s human nature, if I know you for 22 years and that a bond that’s very strong.... Labeling makes the difference. Some people they consider the people that take care of them their friends” (Program Director, South East)

“It can be difficult to walk away from an individual you have cared for, either at the end of a day or at the end of employment, when you have spent a significant amount of time with them, enjoyed their company, participated in activities with them and in some cases become as close as family.”

One participant reported, from another perspective, that individuals who now self direct are hiring peers as support staff and that the individual often becomes part of that staff’s peer group.

“They’re peers of their own age group, so they become part of the social group. ‘Oh, we’re all going out for pizza Saturday night.’ And those [are] support hours but they also become a social experience. This one gentleman was helped out hiking together, and they became friends, and they knew each other’s nieces and nephews. Maybe it’s heading in the right direction.” (Service Coordinator, Statewide)

Clarify Regulations

Recommendations

Illustrative Quote:

1: Better define and communicate the rules on relationships (boundaries) with staff

2: Provide additional clarifying guidance on medication administration rules, including

who can give medications (must it always be MAP certified staff?) and how much flexibility a provider may have in when a medication is administered. There are concerns that fears about needing to report medication errors due to late doses or a non-MAP certified staff administering the medication may impose limits on community experiences.

3: Educate on specific roles that require National Background Checks

4: Clarify new License & Certification Guidelines. Providers expressed confusion about whether the new guidelines around social inclusion measures be considered as important as other guidelines, and whether there will be consequences for not meeting them.

5: Clearly define what DDS means by Social Inclusion and how that will be measured. Providers are fearful that any new policy in this area may mean more rules and regulations, and more reporting.

“I think too the burdensome nature of the bureaucracy, and I can only speak for me, I wanted someone to tell me, am I data, or am I people... I always just wanted to know: People, [or] paper, data?” (Quality Manager, Statewide)

6. Discourage blanket rules that restrict people’s rights to have guests in their homes, communicate with others, or have intimate relationships. Rules that prohibit people to have unsupervised guests in their homes, or limit communication to certain hours or modes adversely impact their ability to form and maintain friendships.

Segregation

Participants identified policies and programs in place that have a segregating effect on people with IDD. This effect may be due to certain aspects of the program, or timing of activities. For example, some participants mentioned that while Special Olympics was well-meaning and exposed people with IDD to activities they may not otherwise be able to participate in, it was not always integrated. Additionally, agencies or providers working in the community often don’t realize they are perpetuating the separation. One participant shared about her son’s art work:

“He... shared about his photography. [The agency] was like ‘Oh, you know there’s an

art show coming up in a gallery in a few weeks' ... I expected information about an art gallery in a community... You know what? ... it was only for individuals with disabilities... to be displayed in a library. What message are we giving to our communities? Stop. Stop.” (Parent, South East)

Other participants mentioned the timing of activities – many volunteer opportunities and recreational activities for people with IDD occur during the day when contemporaries are at work, making it difficult to find friends who are of similar age and have similar interests. Maintaining social connections can also be difficult as young adults age out of school and friends there move on to college.

“People with disabilities go bowling Sunday at 10 AM. I would probably – If I were to bowl – go to Friday/Saturday night at eight. We’re going to a place where there are two other people, probably from a group home, four lanes away.” (Program Director, South East)

Devalued Relationships

Self advocates felt that their relationships with friends with disabilities were often devalued furthering their sense of isolation. Participants expressed concern that like “all of us” we connect with those that have similar experiences and therefore it is important not to devalue the relationships the individual does maintain.

“Some are creating natural supports but the reality is that we all like to connect with people who have shared ideas and shared needs. If we look at our own social networks, we gravitate to the people who have the same strengths and disabilities that I do. Share a common understanding are the most successful relationships.” (Exec Staff, South east)

“... because most of my friends understand my needs. When it comes to making new friends, I dunno if it’s just with me, some people don’t understand what I go through. Even sometimes my close friends don’t -...” (Self Advocate, North East)

Recommendations	Illustrative Quote:
1: Increase opportunities for people with IDD to participate in Unified Sports in addition to sporting events that are only for people with disabilities.	<i>“[Special Olympics is]... crown jewel of sports activities but now there are more options. There might be differences between town recreation programs and Special Olympics and there is a tension in wanting to support people’s choices but letting people to know there is a broader range of options than may have previously thought. We see our role as helping people find and feel comfortable with compatible resources and people.”</i>

2: Increase access to community-based flexible supports	<p>(Executive Staff, Metro)</p> <p>“There maybe one natural piece, which is CBDS. Moving away from sheltered services and moving into community based supports, most individuals are funded full time in community based space that were more funded in a more sheltered environment. The ones who do it well, they do a good job at this.”(Area Director, Statewide)</p>
3: Increase community support; establish relationships with the community so that they see it as their role to welcome participation of people with disabilities or that they reach out to group homes, shared living homes or others living in the community	<p>“I’d like to see having engaged the community where there’s an initiative from the community entity to work from their end to outreach us” (Area Director, Statewide)</p>

Funding

Participants identified a need for additional funding to address a myriad of social inclusion activity including staff, trainings and activities. Participants also recognized that additional funding alone will not solve all of the barriers. Participants emphasized the need to be strategic about where to apply the funding and ensure available funds are used for more inclusion programs. Participants reported, that in some cases, recent additional funding went to support other roles at agencies, such as a fundraiser, rather than to direct support wages or for additional staff in roles supporting community engagement.

Additionally, people with IDD themselves often do not have funds to spend on social and recreational activities. Living on a limited income often does not leave money for ongoing activities or to join a gym for example. In some instances, providers use funds they have ‘fundraised’ to supplement a person’s money so that they can participate in an ongoing activity.

“I think we all recognize that funding is important. It’s not just about money though.”
(Residential Supervisor, North East/Metro)

“Some people have no income, so how do you do activities?” (Human Rights Coordinator, West)

Funding

Recommendations	Illustrative Quote:
1: If additional funding is provided to agencies, ensure it is targeted at appropriate training, finding ways to	<i>“DDS always talks about it but doesn’t really fund it. If they want it to work, need to allot funding so that providers can hire</i>

maintain staff, and increase pay (as described above).

coordinators. These types of programs have not been historically supported. It was removed from licensing focus (many were not displeased to see it taken out of licensing process) but DDS has to put some resources into it.” (Executive Director, South East)

2. Ensure certification indicators regarding social inclusion are included and valued in the evaluation process

3: Explore strategies to address limitations imposed by staff wages and staff ratios/availability, including possibilities for use of non-staff and other community resources to support social activities.

“... what we could use. ... Better rates, to improve staffing ratios to create those friendships. There needs to be money there, if we go to a community event, we want to go out and meet people. We need small groups with staff of 1 to three, four, which right now the rates don't really support... Rate changes could be good. Relooking at rate changes. “ (Program Director, North East/Metro)

4. Explore options to direct funds toward items that support inclusion, such as vehicles, technology (tablets) or recreational activities.

Transportation

Participants reported that access to transportation is an ongoing issue. There are few public transportation options in the suburbs and transportation schedules may present other limits such as no public transportation at night. Because many people with IDD rely on public transportation, these limitations restrict their ability to participate in the community easily, and on a regular basis, or to accept employment in second and third shift positions. In addition, self advocates report that it can be difficult to gain and maintain eligibility approval for “The Ride²”.

“I went to reapply a month ago, and I got denied... I feel I have to go with someone otherwise I feel like I'm going to lose it. I feel like I was discriminated against, even though I know it's not true.... The hardest thing that ever happened was being denied for something, especially when you know the ride is something that you really need.” (Self advocate, North East)

Other participants corroborated these feelings, adding that they expect to have to go through the eligibility process for this service multiple times to gain access and that

² The Ride, operated by the MBTA provides transportation to participants, who cannot access traditional bus or subway transportation due to physical, cognitive or mental disability.

renewals of eligibility were not assured despite the persistent nature of their disabilities.

Reliance on family and friends for transportation can generate feelings of dependency and limits to independence. A person with a disability stated, *“I hate being dependent on other people, I rather be independent...Having people give me rides is nice, don’t get me wrong, but at the same point, it makes me seem less independent, even though I’m not.”*(Self Advocate, North East). Self advocates expressed some frustration at limitations on transportation support in their ISPs; for example, they had services to travel to the doctor, but not to do other activities in the community that were important to them.

Both concerns and confusion arose about whether it was permissible for people to use newer ride sharing models such as Lyft and Uber. Participants discussed that while these may, at times, provide more affordable transportation some safety concerns were expressed.

Transportation

Recommendations

Illustrative Quote:

1: By working in partnership with the MBTA, DDS may be able to help mitigate some of the service eligibility approval challenges faced by people with IDD.

“Right now, on a scale of 1 – 100, my stress level is at 30%. I Right now I have to rely on coworkers, helping me out, getting me here to work.” (Self advocate who had recently lost eligibility for “The Ride”, North East)

2: Consider providing or encouraging provider agencies to provide Travel Training for people with IDD to learn to use public transportation for regular routes on their own.

3: Clarify whether there are any restrictions on the use of ride sharing and other vendors as vehicles for transportation.

Other Challenges

Participants of the focus groups reported on several challenges encountered to community inclusion:

- Overcoming negative social experiences: some people with IDD still carry with them experiences that include lack of social exposure while growing up or being left out as a child.
- Behavioral Concerns: Some people with IDD may act inappropriately either physically or sexually. Social skills training may be helpful for some.
- Matching Volunteers: Some volunteer programs such as Best Buddies provide

companionship for a period of time, but there can be a risk of a negative experience when the volunteers move on. Self advocates reported being left with a sense of loss after their “buddy” stopped contacting them. The loss of the frequently resulted in hurt feelings, frustration and confusion at the Buddy’s lack of response. The temporary nature of these matches may not result in fully reciprocal relationships, and this may not be understood by the person with the disability.

- **Communication challenges:** Some people with IDD have speech difficulties, lack of social skills and an inability to read social cues which can make social interaction difficult. One provider commented:

“People have a hard time understanding him when he talks so they just give up. He gets very frustrated” (Shared Living Provider, West)

Sometimes it’s the other people’s perspective that limits someone’s involvement in the community: the community itself may have a limited view and make a person with IDD feel unwelcome. Several groups talked about the perception of the “white van” and a group of individuals with IDD participating in an activity together, the group intimidates people and reinforces stereotypes.

“I had a couple of different situations where people are interacting within the community on one-on-one support. The way they are perceived in the community is very different than if 10 people, all with disability, show up. And you can see folks without disabilities shy away from that. A lot of it is perception. In order to be part of the community, you have to be welcomed into the community.” (Area Director, Statewide)

In another instance, an individual who does not have “the look” of someone with a disability was judged unfairly when they did not respond appropriately in conversation with people in the community.

“He is very articulate and well-spoken and he doesn’t look like a person with a disability, so he looks like he’s being arrogant and rude.” (Parent, West)

Additional Recommendations

1: Embrace Technology: The use of technology is commonplace in arranging everything from dates, to coordinating meet up events for people with similar interests and hobbies. People supported by DDS can benefit from greater access to communication technology.

- Train individual and staff on the safe use of use social networking sites.
- Remove unnecessary and/or blanket restrictions on people’s access to social networking sites, and other communication technologies (phone, email) to allow people ability to communicate with friends.

2: Open communication channels to allow for sharing of information and ideas to

address ongoing challenges. Encourage providers to share stories and models of what's working.

Approaches to Inclusion: What Works

Formal programs & policies for inclusion

Providers reported a number of successful programs and policies in place to support people with IDD's participation in the community. Some of these include:

- Employment: programs that place people with IDD in the workplace and support their inclusion with co-workers
- Matching "friends" programs: *Community of Friends*³ matches volunteers with similar interests to people with IDD and supports the friendship
- Integration into community in everyday life: provider culture that integrates people with IDD into the community in everyday life including work, leisure activities, and family
- Volunteerism: programs that place people with IDD in volunteer positions and work to support inclusion into the role
- Activities such as recreational programs that facilitate participation of people with IDD in leisure activity as a part of a community such as Special Olympics and similar programs or initiatives (Boy Scouts, LIFE⁴ Program, Arc Programs):
- Social Approaches to connecting individuals with common interests (Community Connecting, One Person One Place, It's a Life Like Any Other)
- Training: Strategies for Community Integration Training⁵, Widening the Circle⁶, Dignity of Risk⁷, and other Mass Families Organizing for Change⁸ trainings, allow support staff, families and others to learn about inclusion and how to facilitate friendships
- Matching staff with similar interests to the people they supports: some providers have been working to match staff with people with similar interests. They have found that staff are more motivated to facilitate participation in community activities when they share interest in the activity.
- Community based flexible supports:

³ Beta Community Partnerships

⁴ Living Independently Forever

⁵ Learning Matters, MA DDS, Central/West Region

⁶ The Arc of Massachusetts

⁷ DDS Learning site: <http://ddslearning.com>

⁸ MFOFC, offers a variety of trainings including the Family Leadership Series

“My daughter has a community based flexible support base team. Whether it’s shopping or going out in the community... they have been remarkable with getting her out socially.... there are 4 staff on, they make appointments to do whatever...they can help somebody make a friend.” (Parent, NSCC)

Informal ways to inclusion

Participants reported on several informal ways they work to include people with IDD in the community such as:

- Siblings/relatives including people with IDD in their social circles: In one example, a brother’s friends included the self advocate in their recreational activities
 - Interactions with neighbors: providing support to the neighbors by walking the dog, shoveling the snow, just stopping by to say ‘hi’
 - Regular, consistent exposure to the same group or activity: Several participants mentioned people with IDD attending open mic nights on a regular basis, performing and developing relationships with other bands/musicians; repeated exposure such as visiting the same coffee shop every day, attending the same exercise class every week, etc.
 - Staff/Parent provides social skill coaching: Staff and parents are often the conduit to a social connection with another person and can provide follow-up to sustain the connection after an initial meeting. However they must also know when to step out of the way for the friendship to develop independently
 - Meeting friends online: people with IDD are meeting friends online through social networking sites. In some cases, it leads to in-person meetings (but not always). This may trigger safety concerns and indicates the need for safety training
- “Keep pushing out there [in to the community] and see where it leads you.” (Executive Staff, Metro)*

Conclusion

As DDS moves from an environment of paternalism to one of self-determination, drafting and implementing a social inclusion policy will require time, patience, support, and clear guidance from all involved to implement this vast culture change

“It needs to be a cultural shift between DDS and the provider agencies. The focus needs to go away from water temperature to what are you really doing with your time. The cultural shift needs to be there so we can focus on what’s important with life.” (Residential Supervisor, North East/Metro)

“... movies, malls, meals. It doesn’t count as community time....” (Residential Supervisor, West)

Appendix 1: Steering Committee

Gary Blumenthal, Association of Developmental Disability Providers

Mandy Chalmers, Massachusetts Department of Developmental Services

Anne Fracht, Self advocate

Dan Lunden, Massachusetts Department of Developmental Services

Susan Nadworny, Massachusetts Families Organizing for Change

Rick O'Meara, Massachusetts Department of Developmental Services

Jean Phelps, LifeLinks, Inc.

Jim Ross, Widening the Circle

Rich Santucci, Massachusetts Department of Developmental Services

Leo Sarkissian, The Arc of Massachusetts

Larry Tummino, Massachusetts Department of Developmental Services

Caroline van Bruinswaardt, Mass Advocates Standing Strong

Bertha Young, Consultant

Appendix 2: Methods

The Center for Developmental Disabilities Evaluation and Research (CDDER), held a series of focus groups which included a wide range of individuals from self advocates, families, and providers to DDS staff. Questions focused on learning about individual friendships, experiences on making friends, and with community involvement in developing friendships. The information gathered, including examples of successes and barriers will help DDS to design a social inclusion policy which not only supports these friendships, but helps build inclusive community interactions.

A series of ten focus groups were held across the state that included self advocates, families, direct support professionals, group home managers, participants in Creating our Common Wealth, DDS service coordinators, DDS Human Rights Staff, DDS Quality management staff, and DDS area directors. In addition, CDDER attended a Direct Support Professional Certification Class at North Shore Community College. Four interviews were conducted, three with executive level staff at provider agencies and one self advocate.

Participant Role	Number of Participants
Family Member	12
Self advocate	11
Residential Supervisor	7
Human Rights Staff	5
Area Director	4
Service Coordinator	4
Direct Support Professional, Direct Support Certificate Class at North Shore CC	2 Approximately 20 students
Executive Staff (Provider)	3
Shared Living Provider	2
Case Manager	1
Vocational Specialist	1

Each focus group included a CDDER facilitator, project manager, and a transcriptionist. All groups were recorded for the purpose of note taking. Participants were told about the scope of the project, how the data would be used, and that participation was voluntary. Permission was asked and granted to record audio for the purposes of transcription. On four occasions, a Creating our Common Wealth facilitator joined the group.

Groups were conducted homogenously (within role) to maintain group dynamics within role and encourage sharing of attitudes and beliefs that may be hidden in the presence of people in other roles. Respondents with intellectual disabilities could choose to have supporters

present to aid in their participation. The focus groups took place in a variety of settings, including provider agencies, a community college, and DDS and UMass Conference Rooms. Each participant (excluding executive staff) received a gift card for their participation. The ages of the participating individuals ranged from 18 to senior adult. Four participants indicated English as a second language. Two self-advocate focus groups included support staff.

Region	# of Groups	Participant Roles
North East/Metro	3	<ul style="list-style-type: none"> • Self Advocates • Direct Support Professionals, Group Home Managers, Creating our Common Wealth • Direct Support Professionals Certification Class (North Shore Community College)
South East	2	<ul style="list-style-type: none"> • Families • Direct Support Professionals, Group Home Managers, Creating our Common Wealth
Central West	3	<ul style="list-style-type: none"> • Self Advocates • Families • Direct Support Professionals, Group Home Managers, Creating our Common Wealth
State Wide	2	<ul style="list-style-type: none"> • Service Coordinators, Human Rights, Quality Management • Area Directors

Focus group questions were tailored for each group and focused on what friendships means to people, how community inclusion is supported and what are the barriers to community inclusion. (See Appendix X for questions).

Transcripts were reviewed and coded for themes by two research analysts. Analysis was conducted using Atlas.ti Version 7. A framework analysis was used to extract themes of perceived barriers. The analysis took a social constructivist approach by examining the regular practices that construct and continue isolation and exclusion, and examined those that foster and reinforce inclusion. The lived experience of people with intellectual disabilities was explored, as well as the perceptions about roles, practices and risks regarding inclusion from paid staff, parents and social service leaders. Perceived barriers were compared across groups, and within the context of the amount of social integration efforts. Barriers were categorized into meaningful groups, such as policies, local rules and practices, and intrapersonal factors.