

Building Supportive Communities

Summary

Natural supports are trusted relationships we form throughout our lives with people who care about us and our well-being. They are people who we can rely on.

Because of ableism in society and isolation in our systems, many people with intellectual and developmental disabilities (IDD), their parents, family members, and other primary caregivers do not have access to robust natural supports.

Many people also experience barriers in their communities that send a message that they do not belong.

We must end ableism, discrimination, stereotypes, and stigma that promote a false belief that people with IDD are “separate” and “other”. We must transform communities to be truly welcoming and supportive of people with IDD.

We must strengthen natural networks of support to include people with IDD, their family members, and other primary caregivers. We must recognize that people with IDD can give support as well as receive it. We must embed universal design in community, so all people can participate in meaningful and accessible ways.

People with disabilities and their trusted supporters can thrive when abundant connections are mixed with paid supports to provide full access in community. All of us have a responsibility to build inclusivity into all aspects of life.

Issue

Some people with intellectual and developmental disabilities (IDD), their parents, family members, and other trusted supporters have robust relationships in their communities. However, there are still many people who experience loneliness, isolation, and segregation.

Throughout their lives, many people with IDD have few opportunities to build authentic relationships with people who do not access nor provide services. From an early age, many kids with IDD face barriers to child care alongside their siblings and peers who do not have disabilities. In school, many are segregated in separate classrooms or buildings.

As young adults, many are forced to move from the places they grew up and the people they grew up with in order to access services. Many are funneled into provider-controlled settings where their primary interactions are with paid staff and others who access formal supports. All elements of life are monitored and documented, without the autonomy and dignity to take risks, engage in relationships, and be free. For people who live in homes of their own, many aspects of daily life become controlled by availability of staff.

Paid supports and professional staff are important aspects of a support network for people with IDD. But far too often interactions with paid staff are the only interactions that people with disabilities have on a day-to-day basis. This limits what people with IDD are able to do and when.

Whether living in a home of their own or a group home, “community” often becomes a place to go for a few hours rather than an active network of relationships that foster real belonging. The things that are important to so many – faith and religious practices, volunteering, and hobbies – become “activities” that are entirely dependent on staff availability rather than essential parts of life that enrich, fulfill, and give us meaning.

Many times, if people *are* able to participate in something that is important to them, it is not truly accessible for them. It may not have the physical accommodations they need. It may not be designed to include language access. It may not be culturally relevant. This sends a message that people with disabilities do not belong in their own communities and are not welcome. This exclusion is felt even more deeply by disabled people who are:

- Black
- Indigenous
- People of Color
- people from culturally specific communities
- people who identify as Two Spirit, Lesbian, Gay, Bisexual, Transgender, Intersex, and Asexual
- people living in poverty
- people who experience other kinds of oppression

People with diverse identities often experience even more isolation and segregation.

Members of communities that have been marginalized throughout history, and still experience discrimination today, often do not have access to the natural supports that more privileged people do. Our history of segregating people with disabilities from society, especially those living in poverty, as well as Black, Indigenous, and other People of Color, isolates them from friends, neighbors, and other trusted individuals to call on for support.

Furthermore, many people with IDD, their parents, family members, and other primary caregivers have to navigate complex systems, often without support. They have to spend their time with representatives of the medical, education, and service systems rather than family, friends, neighbors, and others who are important in their lives. Their lives revolve around confusing paperwork, deadlines, and appointments. Because of these complexities and bureaucracy in systems, they often have little time for themselves, partners/spouses, other family members, and friends.

Isolation, separation, and loneliness are experienced by many parents, family members, and other primary caregivers, too. Sometimes, parents and other caregivers of children with

disabilities are separated from peer groups and loved ones because of ableism, discrimination, and stigma.

Many parents and primary caregivers feel the pressure of being the only lifeline, fearful of what will happen after they're gone.

Due to lack of flexible schedules and support from their employers, some parents and other primary caregivers feel forced to leave jobs and careers. Stressors from systems and the lack of support push many spouses and partners apart, rather than together. This can lead to even more isolation and loneliness.

We have designed separate systems that isolate people with IDD, their parents, family members, and other primary caregivers. We do not have the infrastructure of supportive communities needed to ensure they have true belonging.

Ableism contributes to the belief that people with disabilities are too different to be able to have relationships with those who do not have disabilities. The disability service system and the medical community have perpetuated the idea that only paid, trained professionals can properly provide support to people with IDD. Licensing and other requirements prohibit people from accessing non-paid supports.

There is a belief that people with IDD need to access support solely from within the formal service system. This does not acknowledge the important role that others can play – including friends, family members, neighbors, co-workers, volunteers, members of faith communities, and more.

Many people who do not have disabilities do not understand their capacity to become a friend or supporter, because they have been conditioned to believe "special" systems are the only way to provide that support. They do not know, understand, or believe that society must be transformed to fully include, welcome, value, and respect disabled people in all aspects of community life.

Position

Everyone – including people with disabilities – depends on natural supports. Natural supports are the trusted relationships we form throughout our lives with people who care about us and our well-being. We may go to them for help, guidance, or advice. They are people we enjoy spending time with, and doing fun things together.

Some examples of natural supports include:

- parents
- family members
- chosen family

- friends
- coworkers
- faith communities
- neighbors
- and more

These people often provide support for us without being paid, because there is a natural connection. These relationships are two-sided; we give support as well as receive it.

Sometimes we use the terms “informal supports” and “supportive communities” to describe these connections.

Examples of natural or informal supports include:

- neighbors who help mow the lawn or shovel snow
- friends with same-age kids who help take care of children during an errand or even just to nap
- teachers and guidance counselors who help explore our education options
- coworkers and mentors in our jobs and careers
- someone who might give us a ride if we need it
- people who have the same hobbies, skills, or interests and enjoy spending time together
- people we share our dreams, hopes, and secrets with
- people who help us navigate different stages of life

When we have abundant natural connections and supportive communities, we thrive.

Because of the segregating nature of ableism, racism, and other systems of oppression, some people with IDD, their parents, family members, and other primary caregivers often do not have many natural supports.

We must end ableism, discrimination, stereotypes, and stigma, and the false belief that people with IDD are “separate” and “other”.

We must build and strengthen natural networks of support that fully welcome and include all people. The responsibility to transform communities to be truly accessible lies with all of us – not only those with disabilities and their caregivers.

Community partners, within and outside of the disability community, need to be engaged as part of circles of support.

Building Supportive Communities from an Early Age

We must work to foster inclusion and belonging from an early age, to promote long-term friendships and support networks.

Child care providers must have access to training and resources they need to support kids with disabilities in inclusive settings. Individualized supports should be available on-site as needed.

All facets of our education system must be equitable and accessible, so children, youth, and young adults with and without disabilities are able to learn alongside each other. [Studies show](#) that all children benefit from learning in inclusive classrooms, where differences are celebrated rather than separated. ⁱ

Friendships formed in school can last well into adulthood leading to job opportunities, roommates, and other kinds of meaningful relationships.

Other position statements like “[Employment](#)” and “[Self-Direction in Disability Services](#)” discuss the importance of supportive communities throughout adulthood and across the lifespan.

Building Supportive Communities for Trusted Supporters

Parents, family members, and other primary caregivers need strong networks of natural support, too. They should have opportunity to build long-term connections. These networks can be a source of friendship, support, information, and resources.

With more natural supports, parents, family members, and other primary caregivers are less likely to experience burnout and have time to take care of themselves. These networks of support can also supplement paid child care, making it easier to maintain jobs, careers, and other priorities outside the home.

Employers should make accommodations for parents, family members and other primary caregivers, too, to promote a healthy work-life balance.

Intergenerational families should be supported to care for each other across the lifespan – including for family members who have disabilities.

Supportive Communities and Formal Services

It is critical to pair supportive communities with robust, individual services that meet people’s diverse needs. Unpaid, informal supports should be supplemented by a flexible system that allows people to pay trusted supporters a living wage. People must be able to choose their own staff from within their network of friends, neighbors, faith community members, and others. When there is a natural connection established, the quality and sustainability of support is more likely to improve.

People who do not have access to informal supports must have a range of flexible individual services that meet their needs. All services should have a focus on supporting people’s belonging in communities so they can build meaningful relationships of their choice.

Universal Design

Society must commit to universal design in our community infrastructure. The places and spaces where people gather have to be accessible and meet individuals' needs so everyone can fully participate in all areas of life. Eliminating barriers and fulfilling people's unique access needs can promote supportive and accessible communities. The responsibility for doing so lies with all of us.

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ⁱ Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., Burke, S. (2016, August). A Summary of the Evidence on Inclusive Education. *Instituto Alana*.
http://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf