Empowering Choice: From Pizza to Politics

Disability Rights Washington
Washington's protection and advocacy system
Letter from the Executive Director

Stigma, ignorance, misinformation, insufficient resources, paternalistic attitudes, low expectations, lack of adequate transportation, unavailability of the internet and inadequate or inappropriate supports are all used as excuses for why we have not fully realized our widely shared vision of inclusive communities where people with disabilities are engaged with their fellow citizens and able to make the decisions affecting their own lives.

However legitimate these excuses may be, they do not adequately explain why there are some supported living programs that do an excellent job of supporting people to achieving this vision, yet at the same time there are providers who miss the mark in some significant way. In short, why is it that some supportive living programs are able to change where people live, but fail to change how people live?

This report begins to explore the why. Why are some programs able to overcome or mitigate the barriers that exist to successful community engagement and some are not. For Washington, we don’t think the answer lies in a lack of the vision of full community living or the guidelines written to help residential programs implement that vision. Washington State’s Residential Service Guidelines were written 25 years ago and are still, for the most part, relevant today.

Nor do we think there is a lack of model, best practice programs to show us the way. Much of what we would like to see for all of Washington’s residents with intellectual and developmental disabilities is already being experienced by many of our residents due to the hard work and innovation of supported living program employees throughout the state.

Rather, we believe sharing what we observed and learned from visiting a variety of supported living programs will help us all understand why things are as they are and to find solutions. We want to see the best practices of a given supportive living program spread to all supportive living programs.

The DRW project that resulted in this report started out being about voting and how to help people with intellectual and developmental disabilities to fully exercise their rights. But it evolved into something much more that. Certainly, there are people with intellectual and developmental disabilities who with the right information, equipment or minimum of support would have no problem exercising their right to vote. For others, however, the successful exercise of their right to vote is intertwined with everything else
they are learning and experiencing about how to make decisions affecting their lives and become engaged in their communities. It is not just about learning some technical aspect of voting. It is about giving people who lack them, the opportunities and learning experiences necessary to become integral contributors to their communities.

We fully understand that some of the obstacles to full community living are bigger than any one supported living program can address. And we at DRW are committed to working with other stakeholders in seeking systemic reform. But in the meantime there is much progress to be made on things that are within the control of DSHS and its supportive living providers and we hope this report will contribute to your efforts to make the lives of people with intellectual and developmental disabilities fuller.

Mark Stroh
Executive Director
Empowering Choice: From Pizza to Politics
Edited by Sarah Haywood Eaton

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EXECUTIVE SUMMARY

This report discusses DRW’s observations of everyday ways in which Supported Living providers can either facilitate or hamper people’s abilities to wholly engage in community life as equal society members, as articulated in the Residential Guidelines. In sum, DRW identified examples in three areas of decision-making and community engagement where people with disabilities participating in Supported Living programs can be supported to increase their political enfranchisement:

1. Provide Access to Information and Communication
   a. Individuals need information about their rights to vote and how to exercise those rights.
   b. Access to modern internet technology is a critical tool for people with disabilities to participate in modern democracy.

2. Support and Training to Exercise Autonomy and Self-Determination
   a. Everyday practice in making basic personal decisions can provide habilitative training and support to gain increased capacity to assert broader and more complex political choices.
   b. Messages that people receive through daily interactions can either reinforce or challenge individual autonomy, responsibility, and self-determination.

3. Encourage and Support Opportunities for Community and Civic Engagement
   a. Integrated activities that provide for contact with members of the general public can enhance interest and awareness in the social and political issues of the communities to which people have a strong sense of belonging.
   b. As members of the general community as well as participants in their Supported Living programs, people need the skills, opportunities, and networks to serve as the agents of their own advocacy to improve public and program policies.
DRW’s observations indicate that individuals receiving support in these three areas were either experiencing or on the pathway to experiencing a full and equal enfranchisement, while others were obstructed in gaining increased capacity to exercise choice and learn more about their communities. In sharing these examples, DRW hopes to engage individuals receiving support, providers, policy makers and policy advocates in a discussion about how Washington’s service delivery system can more comprehensively enfranchise individuals with developmental disabilities as full and equal participants in our democracy.
INTRODUCTION

Under Washington State’s Constitution, an adult citizen’s right to vote is fundamental.\(^1\) As a result of both federal and state legislation, voting systems across the country are becoming more accessible for people with disabilities.\(^2\) Most recently, in response to the irregularities in the 2000 presidential election, Congress enacted the Help America Vote Act (HAVA) to provide federal funding and institute new requirements for accessible voting places.\(^3\) In Washington, voters can cast their ballots by mail independently, or if they need help, with assistance from anyone other than their employers or union representatives.\(^4\) Voters with disabilities can also cast their ballots at accessible polling places where they can receive assistance from a member of each political party, or by using an accessible voting unit.\(^5\) Moreover, in 2005, Washington’s legislature removed a presumption that full guardianships over people with mental disabilities automatically deprive individuals of their fundamental right to vote.\(^6\) Just as political enfranchisement has been a hallmark of the civil rights movements for women and people of color, removing voting barriers such as these is essential to providing equal and full enfranchisement for people with disabilities.

During the summer of 2013, Disability Rights Washington (DRW) conducted a statewide monitoring and outreach project to provide voting rights information to individuals with developmental disabilities receiving community-based Supported Living services and to learn how their service providers support them in their everyday lives. Across the state, DRW met individuals who proudly reported that they were registered to vote and discussed positive experiences with the electoral process. Some individuals said that they had staff or family members assist them in reviewing voting materials and filling out their ballots, while a few stated they were able to exercise their voting rights with little or no help. However, in almost every Supported Living program, DRW encountered people who remained disenfranchised. For some, this was due to misconceptions about their voting rights. But for many, there were also barriers reflecting broader limitations in the person’s integration into the community, and power to make decisions.
During these visits, DRW found examples of people who are able to exercise independent decision-making and engage with their communities. This ability to make choices is a critical component of broader political enfranchisement. Autonomous decision-making and community engagement are cornerstone concepts that pervade Washington State’s Residential Service Guidelines (Guidelines). These Guidelines were established in 1988 by the Department of Social and Health Services (DSHS). The Guidelines were adopted in the midst of a burgeoning national movement away from isolated and congregate-based care towards community integration. The right to choose to live in the community with support was affirmed a decade later in a landmark civil rights U.S. Supreme Court decision, *Olmstead v. L.C. ex. rel. Zimring*. The Guidelines were adopted at the height of the integration movement in Washington State. These six principles encapsulate the essence of full and equal enfranchisement:

1. Health and Safety;
2. Personal Power and Choice;
3. Personal Value and Positive Recognition by Self and Others;
4. A Range of Experiences Which Help People Participate in the Physical and Social Life of Their Communities;
5. Good Relationships with Friends and Relatives; and

These Guidelines extend well beyond a description of residential locations and physical structures. The Residential Services Guidelines affirm that deinstitutionalization and integration are not just about where people live, but how they live. All six elements of the Guidelines provide for a day-to-day life marked with personal empowerment, autonomy, and community. This report discusses how daily implementation of these Guidelines can create the foundation for empowering a person to participate in shaping our society and government, as well as to self-determine his or her own everyday life.
BACKGROUND

Disability Rights Washington (DRW)

Disability Rights Washington is a private non-profit organization that serves as the designated Protection and Advocacy System for Washington State. DRW’s mission is to advance the dignity, equality, and self-determination of people with disabilities. As a Protection and Advocacy System, DRW carries out its duties using a multi-modal advocacy strategy that includes legislation, litigation, investigation, and education. For more information about DRW, please visit our website at www.disabilityrightswa.org.

Supported Living

Nearly four thousand adults with developmental disabilities who could choose to live in institutions have instead chosen to live in their own homes and receive support through the Supported Living program. They receive in-home support and instruction, and pay for their own housing, food, and other expenses. The people who assist them are employees of state-certified Supported Living provider agencies, which contract with the Department of Social and Health Services’ (DSHS) Development Disabilities Administration (DDA). DDA pays for Supported Living services with Medicaid funding under the Core and Community Protection Home and Community Based Waivers. Unlike other DDA services, the residential habilitation services offered in Supported Living are designed to provide support for personal care in addition to supports to “learn, improve, or retain social and adaptive skills necessary for living in the community” and instruction and support for achieving one or more of the outcomes described in the Guidelines.

Unlike other DDA services, the residential habilitation services offered in Supported Living are designed to provide support for personal care in addition to supports to “learn, improve, or retain social and adaptive skills necessary for living in the community” and instruction and support for achieving one or more of the outcomes described in the Guidelines.
Purpose and Scope

The purpose of this report is to identify ways to improve people's ability to engage in community life as full participants by discussing concrete examples that illustrate typical, everyday lives of individuals receiving Supported Living services. This report is not intended to provide a data-driven analysis of Washington’s community services, and barring a few exceptions,15 does not identify system-wide “trends.” None of the examples compiled in this report should be interpreted to indicate or imply prevalence or lack thereof for any particular practice or outcome. Instead, this report is intended to spread good ideas as well as to raise awareness about practices and attitudes that contribute to disenfranchisement. It will be used to start a dialogue about decision-making and its role in voting and civic engagement and how people with disabilities receiving Supported Living services can best be supported to increase decision-making skills and capabilities.16

Methodology

DRW conducted in-person interviews and made on-site observations to share and gather information. In June and July of 2013, DRW staff visited the homes of people receiving Supported Living services from fifteen providers of different sizes in Cowlitz, King, Kitsap, Pierce, Snohomish, Spokane, and Yakima counties. Although a few individuals did not choose to meet with DRW, over seventy people voluntarily talked with DRW about voting and their Supported Living services or allowed DRW to see their homes and observe the types of supports they were receiving. Additionally, DRW conducted interviews with dozens of staff and administrators in order to ask how they believe they support their clients in reaching the outcomes described in the Guidelines.
DRW thanks the many individuals who welcomed DRW staff into their homes and shared their stories, as well as Supported Living staff and administrators who candidly described their programs and the current service delivery system.

OBSERVATIONS AND ANALYSIS

Access to Information and Communication

1. Information about Individual Right to Vote and How to Exercise It

Knowing about the right to vote is one of the first prerequisites to being able to exercise it. While some people with disabilities cannot vote because they have a guardian, not all people with guardians have had their right to vote removed. Whether the person retains the right to vote when his or her guardianship was established depends on the specific language of the court order and when the guardian was appointed.\(^{17}\) Only full guardianships established before July 24, 2005, removed a person’s right to vote as the default. With all partial guardianships regardless of when they were established, and full guardianships established after July 24, 2005, people presumptively retain the right to vote unless otherwise stated in the court order.\(^{18}\) No one loses the right to vote simply by virtue of a disability. Although the right to vote is fundamental, DRW found individuals both with and without guardianships who indicated they had never considered voting or considered the fact that they were allowed to vote.

During DRW’s visits, multiple providers told DRW that when the issue of voting came up during service planning meetings with DDA case managers, people’s guardians or non-guardian parents would state the person should not be allowed to vote. Many, if not most, staff and individuals receiving Supported Living services indicated assumptions that regardless of the type or timing of a person’s guardianship, the person’s guardian or even non-guardian family members had the authority to
determine whether or not a person could vote. In one instance, a house manager reported that an individual could not vote based on her mother’s directive, even though the individual did not have or need a guardianship. The house manager was surprised to learn that the choice about whether or not to vote was strictly the individual’s. One person’s staff stated the person’s guardian/parent said the provider should not help the person register to vote because the guardian was concerned that rather than making her own independent choice, the person would simply vote the way her family voted. Even after DRW would explain how guardianships may or may not affect a person’s right to vote, many people still were unsure about whether they were allowed to vote because they did not know when their guardianship orders were entered or what the orders said.

The Right to Vote and Guardianship

Only a court can make a person ineligible to vote due to lack of capacity. There is no basis for assuming that a person who has a guardian cannot vote.

Guardians, family members, and others do not have the authority to vote on behalf of the person. They also do not have the right to decide whether or not the person will vote.

In a guardianship a court may decide to take away a person’s voting rights, where it finds that the person lacks “capacity to understand the nature and effect of voting such that she or he cannot make an individual choice.”

A person may be supported in learning “the nature and effect of voting” so that she or he can make voting choices.

If after this support the person wishes to vote, she or he can petition the court to restore the right to vote.

For information on the right to vote see the Washington State Secretary of State’s website:
http://www.sos.wa.gov/elections/voters.aspx (click on “Voter Eligibility”)
In addition to not knowing whether they were eligible to vote, DRW found people faced voting barriers due to a lack of information about how to vote in both a practical and political sense. People were unaware that they could request assistance from their staff to read and fill out their ballots, and several staff voiced concerns that offering this assistance would result in actual or perceived undue influence over how the individual would vote.20 One person who needs help reading and filling out her ballot stated she chose not to vote in the last election because she wanted to cast her votes privately, but she and her staff were unaware until DRW’s visit that this was feasible with accessible voting units that provide for ballots to be read aloud and cast via a touch screen, wheel, or other tool.21 Others simply expressed lack of knowledge about political issues or candidates as a reason they chose not to vote.

2. Access to Internet Technology

This lack of knowledge about voting and politics that DRW observed is not for lack of existing information. DRW’s website has voting information materials,22 and the Washington Secretary of State’s office has a webpage dedicated to voting,23 as well as information specifically for voters with disabilities,24 voters with guardians,25 and voters with past criminal convictions.26 People can go online to access voter’s pamphlets, request voter’s pamphlets in alternative accessible formats, conduct their own research on candidates as well as initiatives and referendums, stay up to date on news and current events, use social networking to express their own political views and read about those of others, find out about in-person community and political events, and communicate with political leaders.27 Through software and technology, much more material can be made available in various accessible formats and mediums, which is making it easier than ever for people with disabilities to get information. In short, the internet is now one of the most significant tools for any person, with or without a disability, to participate in a modern democracy.28

However, despite its utility and ubiquity, DRW found that the internet is largely unavailable to Supported Living participants. Although some people DRW met had devices that had internet connection capability, of the seventy or more Supported Living participants who DRW met, only two actually had private access to internet services in their homes. When DRW asked about whether those without internet access had
considered getting internet access or devices, most stated they believed this simply was not an option. As one individual said, “that just wouldn't fly.”

When DRW discussed the lack of internet technology with providers, many cited cost of devices and services as the main barrier, pointing to clients’ limited incomes and resources. However, in the cases where clients had devices, staff worked with them to budget or find someone who would donate a computer. Internet equipment and services can be expensive, but simply assuming internet is unaffordable without exploring low-cost options or cost-sharing and budgeting strategies can deprive individuals of the choice to decide whether internet access is important or preferable to other goods or services.

DRW also heard paternalistic and prejudicial doubts about whether individuals with disabilities could or should use the internet technology. For instance, one staff person agreed that a tablet could be useful for one client who does not use verbal communication, but stated that he would “probably just end up breaking it.” Another staff discouraged his client from trying to obtain private internet access at home, stating the only time he had ever seen the client use the internet at the library was to look up information about video games, a use that the staff did not personally find justifiable. It was said for another adult that a computer was off limits because of “possible sexual content.” The biases expressed in these comments result in limited access to information for people with disabilities.

The internet is now a critical feature of modern life that has empowered billions of people around the world with information they had previously been unable to access. The internet as we know it today did not exist in 1988 when the Residential Services Guidelines were written. The Guidelines acknowledge only that people should have private access to telephone and mail. A quarter of a century later, information
transmitted by mail or telephone is now delivered through email, social networking, and online publications.

The lack of internet technology crosses over almost every area of the Guidelines. At a home without internet access, a person receiving Supported Living services discussed difficulty in finding work. Another client expressed frustration with keeping in touch with friends and family. One person indicated he could go to the library to use public internet, but would have preferred to have a connection in his home that he could access anytime, since getting to the library was not always feasible due to limited staff or transportation, and computers were not always available at the library. People without internet access faced barriers to getting information about issues and events and to advocating or participating in political processes, which were exacerbated by transportation limitations. Given how important internet technology is for people with disabilities in 2013 to connect to their communities and thus exercise their right to vote and engage in a range of other civic activities, Supported Living providers can address this unmet need for support by seeking out resources to traverse the digital divide in order to maximize people’s political, social, and economic empowerment.32

Support and Training to Exercise Autonomy and Self-Determination

3. Practice in Everyday Decision-Making

As a number of Supported Living staff pointed out to DRW, exercising the right to vote also requires skills and interest in exercising decision-making power and expressing individual choices. While many of the staff and administrators DRW met expressed interest in learning appropriate ways to assist a person in exercising choices about voting,33 DRW also heard staff insist, even in the presence of the individual they were supporting, that it would be futile to even discuss voting because the person “would never be able to vote.” Although it may be true that some people lack a current motivation or capacity to make or express voting
choices, DRW talked with many other staff who, rather than making disparaging comments about a client’s disabilities, made supportive statements acknowledging clients’ potential to perhaps gain this capacity or interest over time. Indeed, the Supported Living program is specifically designed to provide individualized habilitative services that support each person to continue gaining new skills throughout his or her life.\textsuperscript{34}

According to the guidelines, the ability to exercise and express choice is something that Supported Living providers are supposed to develop.\textsuperscript{35} Developing these skills might ultimately help to increase capacity for making other kinds of more

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**Accessible voting**

In recent years there have been many changes in elections that have improved the accessibility of voting for people with disabilities.

Voters who can’t read or mark a ballot can now vote in private. It is no longer necessary to ask someone else to read the ballot to the voter.

People who cannot read a printed ballot, or are unable to mark a ballot, can vote privately on an “accessible voting unit” (AVU). These machines can provide the ballot on a screen, and the voter can select by touching the screen or using a select wheel or tool. The voter can use headphones to listen while the AVU reads the text of the ballot. The machine is a computer, and most allow the use of switches that can assist individuals who cannot mark a printed ballot.

These machines are very well adapted for use by people who have intellectual or learning disabilities, and cannot read a ballot. The voter can receive instruction and assistance in using the machine by staff at the polling place, and can have assistance by another person of his or her choice.

The machines are available for use for the 18 days preceding an election at the county auditor’s office, and frequently in other locations. Consult your local auditor for locations and more information.

*For information on accessibility for voters with disabilities, see the Washington State Secretary of State’s website: https://wei.sos.wa.gov/agency/osos/en/voters/Pages/voters_with_disabilities.aspx

There will also be information about accessible voting at your local county auditor’s website.*
complex decisions, including decisions about whether and how to vote. As the “Power and Choice” guideline articulated twenty-five years ago, people receiving community based services should obtain and maintain “power, control, and ownership over their personal affairs.” Similarly, the guideline for “Competence” stresses the importance of individual choice and empowerment:

“Competence is the capacity to do what you need and want to do. There are two ways to be competent. You may be self-reliant and able to do things for yourself or you have the power to identify and obtain the help you need from others.”

Together, the guidelines for “Power and Choice” and “Competence” establish expectations that providers support individual capacity and freedom to maximize individual decision-making. As the Guidelines point out, “residential programs should take positive actions to protect and promote the dignity, privacy, legal rights, autonomy and individuality of each person who receives services.”

DRW observed examples of individuals’ power to make daily choices about their own lives. In particular, DRW noticed that in some homes the decision about what and when to eat and drink is a choice that some individuals make for themselves while others had the choice dictated by their Supported Living staff. DRW also noticed people have varying levels of opportunity to individually choose their own activities.

DRW learned about several ways providers offer opportunities, education, and support for their clients to make their own food choices without rigid restrictions that deprive individuals of their ultimate daily decision-making power. For instance, staff assist people to shop for their own groceries with reminders and encouragement to

Nutrition plans and schedules were not being used as tools to support healthy individual choices, but rather as inflexible rules that staff felt they were obligated and authorized to enforce. This type of rigidity would not apply to people in the general community who have the freedom to decide whether or not to stick to their plans, diets, and schedules, even if such plans were recommended by their physicians to prevent or mitigate medical conditions.
make healthy food choices. Individuals discussed preparing meals with staff support in addition to going to out to eat at favorite restaurants as ways they can exert autonomy in their food choices. DRW observed one instance where an individual expressed a preference for a specific lunch item after staff had made something else, and staff then assisted him in making the preferred item instead. When one person entered his kitchen and started opening and closing his refrigerator, a staff inferred he may be interested in an afternoon snack and prompted him to use his decision-making skills by asking him, “What looks good?”

DRW also noted providers had found ways to support people in self-determining how they would spend their time. One of the programs discussed how its clients participate in developing the provider event calendar. DRW spoke with one individual who mentioned that planning and throwing her own parties and for other people in the program was one of her favorite things to do. DRW observed one staff person talking to someone she supported about plans to attend a music concert. In these examples, people were given opportunities and encouragement to practice decision-making and planning, which empowered individuals in the moment and helped develop skills for individuals to make other future decisions regarding their community.

However, DRW also found examples where staff reported being in charge of selecting food options or dictating food limits. For instance, people could make special requests for certain foods, but did not control their own grocery shopping. Other individuals could only choose from limited food selections offered by their staff. DRW observed one person attempt to get a cookie from his kitchen cupboard when his staff stopped him and told him his snack options were on the counter. One administrator stated that he considered one of his client’s preference for being supported by one particular staff over the others to be unjustified because the staff preferred by the individual was “allowing” the person to go to a favorite restaurant that was “outside his nutrition plan.” During another visit, a staff scolded a client for telling DRW his favorite food was lasagna, telling the client, “You know you’re not allowed to have that!”
In some homes, people were required to eat the same things and at the same time as their housemates. At two of the homes DRW visited, people were only allowed to choose what they ate for dinner once a week, and soda was allowed only on Fridays. An administrator for a program supporting people living in one of these homes described putting up bells to alert staff when a person was entering his or her kitchen. This, the administrator said, had been a successful strategy for people to “learn we go in the kitchen at mealtime,” explaining that this helped to enforce scheduled meals (i.e. “5:00 is when we have dinner”). During one visit, DRW met a person who wanted to eat before going to a party where lunch was going to be served, but rather than helping the individual make lunch at home or suggesting some lighter snack options, his staff repeatedly told him, “No, it’s not time to eat yet.”

Regardless of whether diet restrictions and mandates such as these are health or convenience driven, they are fundamentally disempowering, deprive individuals of opportunities to practice decision-making skills, and evoke the types of institutional practices that the integration movement has been seeking to eliminate.

In instances like these, nutrition plans and schedules were not being used as tools to support healthy individual choices, but rather as inflexible rules that staff felt they were obligated and authorized to enforce. This type of rigidity would not apply to people in the general community who have the freedom to decide whether or not to stick to their plans, diets, and schedules, even if such plans were recommended by their physicians to prevent or mitigate medical conditions. Although nutrition-related conditions and diseases pose significant individual and collective public health risks in the general population, the freedom to personally choose what and when to eat is a liberty most adults living in their own homes take for granted. Supported Living providers should support their clients to maintain and improve their health, but the Guidelines expressly recognize that Supported Living providers should use “means for protecting health and safety which are not unduly restrictive and are as typical to means used by other community members as possible.” Regardless of
whether diet restrictions and mandates such as these are health or convenience driven, they are fundamentally disempowering, deprive individuals of opportunities to practice decision-making skills, and evoke the types of institutional practices that the integration movement has been seeking to eliminate.

Similarly, DRW spoke with people who wanted more opportunities to do activities other than the limited options their providers were offering. While many people looked forward to provider planned parties, dances, BBQs, camping, and a variety of other provider sponsored activities, a number of individuals expressed frustration over having too few opportunities to self-determine which activities to do. For example, one individual talked about deciding not to go on a house trip to the aquarium, which she explained she felt “was for children.” When asked by DRW staff what kinds of things she would rather do, she talked about taking her bike on a trail ride and going horseback riding, but she said she was sad she had not had an opportunity to do either activity since she moved into her Supported Living home. Another client receiving support form a different program looked down and said “not really” when asked if she enjoyed her house’s weekly outing to the swimming pool. When asked if there was anything else she would prefer if given the choice, she smiled and answered “bowling,” but explained that this was not a regular house activity she had the opportunity to do very often. Rather than offering “people experiences on which to based choices and opportunities to expand the experiences” as described in the Guidelines as an indicator of Power and Choice, these providers were limiting people’s experiences and options, as well as opportunities to discover their own decision-making capacity.
4. Messages About Autonomy, Responsibility, and Self-Determination

Finally, DRW observed staff who enhanced their clients’ confidence and decision-making power, but other staff who introduced and reinforced self-doubts in the people they supported.

As recognized in the Guidelines, having “valued perception by self and others,” or “status” is something that is “important to all people.” The Guidelines specify that “programs should seek to offer assistance in ways that are appropriate to the age of the person, typical to other members of the community and contribute to the person’s feelings of self-worth and positive regard by others.” In some examples DRW witnessed, providers were doing everyday things to support the people they serve to increase their feelings of self-worth, confidence in their own skills, reinforce their self-determination and autonomy, and build in them a sense of responsibility. All of these things are important in people’s daily lives, and are important for enabling people to engage as full participants in a democratic community. However, DRW also noted examples where individuals received everyday messages that they do things wrong, that they are incapable of doing things for themselves, that they are child-like, and that they do not have the same right or ability as anyone else to express themselves through their own voice and narrative.

In a number of examples, DRW observed providers boosting confidence and self-image by offering support to engage in skill and competence building activities, and celebrating accomplishments. One person proudly shared with DRW how he had passed the test for a drivers’ permit and was taking a driving class to one day get his license. He told DRW staff how a staff member made flash cards to study for the permit test with him every evening. Another individual described to DRW his interest in the guitar, and then played the guitar for DRW staff. Several clients listed the responsibilities they had for maintaining their homes and exhibited great pride in keeping their homes and yards clean and attractive. Others talked about helping their communities by volunteering at local nonprofits, such as the animal shelter or food bank. Some people receiving Supported Living services had pictures of themselves with family on the walls in their rooms, as well as sports trophies and medals, art made by themselves or friends, and other keepsakes that symbolized a positive self-image.
DRW met one person who was excited to return home from a lunch with one of his favorite staff, who had taken him out to celebrate his success in independently keeping his own room clean and organized for two weeks.

In contrast, DRW observed a few examples of staff doing or saying things that could diminish anyone’s sense of competence and responsibility. For instance, a staff corrected a person who pushed the wrong button on the microwave to warm up his lunch, impatiently saying “no, that’s not how I told you to do it!” At another house, when a man was emptying his own garbage, a staff person took over and completed the task for him, even though the person did not request or need assistance. Although DRW observed some staff speaking to clients with the same level of respect that any adult would reasonably expect, some staff used juvenile nicknames to refer to their adult clients, spoke to their clients in high-pitched voices, and used patronizing references like “honey,” “so sweet,” “so cute.” One staff repeatedly stated that she treated her clients “like my children” and provided several unprompted examples of ways she felt the adults she supported were child-like. Similarly, one provider administrator described his adult client’s intellectual disability by ascribing to the person a child’s “mental age.” After one individual shared with DRW that she enjoyed “suspense and mystery” movies, the staff expressed concern those kinds of films were “too scary” and
suggested some children’s cartoons that that the person might like instead.

DRW also observed how staff supported people to express their own ideas and decisions. During some visits, staff encouraged their clients to answer questions themselves rather than deferring to staff to answer for them. In one conversation, DRW staff had difficulty understanding a few words a person was saying. Rather than presumptuously interjecting herself into the conversation to interpret, a staff person who was very familiar with the individual’s speech patterns would quietly ask her “do you want my help?” This same staff also demonstrated respect for her client’s autonomy and property by asking her client, “Is it ok with you if I put my snack in your fridge?” With this type of support and respect, this individual was receiving messages that she is competent to express herself and entitled to make decisions.

However, DRW witnessed other instances where staff would automatically answer questions posed to their clients, or gratuitously interpret what individuals were saying without confirming with clients whether they wanted assistance. As an example, when DRW asked one woman how she used her iPad, the woman’s staff member grabbed the iPad from her hands without asking permission rather than letting her show DRW how her own device worked. Some staff would openly contradict or discredit their clients. One devalued the volunteer work a person was proudly describing to DRW when the staff person teased that her client merely “visited” people working in an office. The staff went on to suggest that the woman was merely a distraction in the workplace, and laughingly told the woman that “You make them take breaks.” During another visit, a staff member referred a person’s employment as “her little job.” While one person was telling DRW about working out at the gym, his staff stood behind him and silently mouthed “never.” At the beginning of another visit, a staff member shook hands with DRW employees, but then did not allow the client to shake hands, explaining to DRW, “You don’t want to shake his hand because you never know where it’s been.” With any other adult, interruptions and statements like these would be considered rude and humiliating. Nonetheless, in this context, it appeared to be tolerated, if not accepted, for staff to belittle their clients. While people often ignored or appeared to acquiesce to being interrupted, contradicted, or even insulted, these kinds of staff actions do not
contribute to an overall sense of self-worth or equal enfranchisement that people need in order to feel entitled to assert their political power.

Opportunities for Community and Civic Engagement

5. Opportunities for Integrated Activities

In addition to having information and capacity to make decisions, community engagement is also a factor in exercising the right to vote. Washington has recognized in its Guidelines that people with disabilities “should be present and actively participate in the community using the same resources and doing the same activities as other citizens.”

Under the Guidelines, people should have a “range of physically and socially integrated experiences.” Unlike segregated settings that “provide for daytime activities primarily with other individuals with disabilities,” the Guidelines specified that community participation requires options for “activities and places of interest which are available to all members of the community,” a selection of “personally meaningful activities,” and a “balance” between activities with paid staff and co-clients and activities involving “other members of their community.”

Practically every individual, staff, and administrator DRW interviewed talked about visiting public places and patronizing community businesses as a way to engage in the community. Though it may still sometimes occur, DRW did not hear of any reports that people ever felt unwelcomed or discriminated against when they went to public places. To the contrary, people enjoyed going to local restaurants, shops, and community centers where they were not only provided warm friendly services, but also known, often times by first name. One administrator shared that when one of his clients had stayed home for several days recovering from an illness, a clerk at the convenience store where the person went every day to purchase a soda called the provider’s office to check on how the person was feeling.

However, DRW also noticed that the ways in which people “get out in the community” is often still segregated. One administrator answered “Special Olympics” when DRW asked for an example of how that program supports integration in the community. Accordingly, people receiving services from that provider as well as other agencies told DRW staff that they could participate in a sport during the Special Olympics, but did not have opportunities to do so during other times of the year whether
it be independently, informally with friends, or with integrated leagues or teams. Others talked about attending social clubs or classes specifically designed for people with disabilities to explain how they participated in their communities, but could not offer other examples of regularly participating in activities organized for members of the general public. A number of employed individuals had segregated jobs in sheltered workshops or work enclaves or crews with other vocational services clients who have disabilities. While segregated activities may be enjoyable as well as skill developing for some, providers that over-rely on these types of separated activities to support a meaningful schedule of community activities for their clients are not providing “opportunities for contact with non-disabled persons” to the “fullest extent possible.”

Lack of personal funding to participate in activities was one of most commonly discussed barriers for individuals to participate in individualized and integrated recreational and community activities. However, some providers devised creative ways to support people to take part in an array of integrated activities despite limited resources. For instance, rather than simply making a static program calendar of provider-sponsored parties and outings, a bulletin board with an array of flyers and listings of free and low-cost events around the community served as a visual reminder and information source for individuals and their staff to find affordable options. An annual event to raise financial aid funds for those who could not afford more costly recreational activities was another reportedly successful strategy. One agency talked about seeking event ticket donations as a charitable contribution, in addition to perpetually looking for various discounts.

Provider staff and administrators also discussed the role of staff in supporting community engagement. An administrator reported that he and his managers consistently encourage staff to help the program’s clients stay “active and engaged,” and explained his expectation that when individuals say “let’s go, it means we go.” In some instances, staff would explain that a person needed a higher staffing level than was available to support an outing to the community. When one individual told DRW that she had been asking to go swimming all summer, her staff jumped in to say “we’re working on that.” The staff explained to DRW that they had been trying to make
arrangements for her to go to the local pool as she had been requesting, but had not been able to do so because of staffing levels and her housemate’s health needs.

In the Community Protection Program, DRW met a number of people who needed to have a one to one staff ratio if they were in public, but their Supported Living programs had limited and inconsistent capacities to provide that level of support. For example, DRW visited one home where the staff and the clients reported the clients had been unable to go out in the community due to staff vacancies. One of the clients made repeated requests for DRW staff to take him to the store. Another Community Protection service provider discussed making great efforts to assist their clients in identifying natural supports in their lives to supervise them in public. This, they explained, required going through an often drawn-out process to get approval from a therapist and the state, but was critical for enabling people to stay involved in the community and with their friends and family.

Similarly, access to transportation is a significant factor in and can be an indicator of the level of people’s community engagement. DRW did not meet a single person receiving Supported Living services who owned a personal vehicle that he or she could use at any time, and met only one person receiving supports necessary to one day obtain a driver’s license and personal vehicle. As a result, most Supported Living clients will rely indefinitely on their providers, other supports, or public transportation to leave the immediate vicinity of their homes.

In areas with public transportation, DRW found examples showing some people face barriers in using it. For some, providers did not support them to use public transportation. Reliance on program-provided transportation is in and of itself a segregated way to provide transportation support and limits a person’s ability to engage with his or her community. For instance, at one house located on a main bus line, a staff member told DRW that all the clients he supported had bus passes, but he could not think of any time they actually used the bus instead of the provider’s van. In that house, the clients answered, “Nothing, we watch TV,” when asked what kinds of things they liked to do during the day. The staff member explained that they were not able to use the vans very often for fun activities, because the vans were typically already in use for transportation to things like doctor and therapy appointments.
Other people cited convenience and safety issues as barriers to using public transportation. A few people who used paratransit discussed how the lack of flexibility for rides that had to be scheduled at least twenty-four hours in advance limited their ability to engage in spontaneous activities or to alter their plans, and that there were long wait times to get picked up by the paratransit bus so simple outings could take several hours. A couple of people who use wheelchairs talked about having safety concerns with public transportation because the sidewalks in their two different cities were in such bad repair that in order to use bus stops, they had to go into oncoming traffic in the street.

In less populous areas of the state, people do not have access to reliable public transportation. This is particularly problematic for people whose provider offers only limited transportation options. One program whose clients do not live near bus lines had imposed a fifteen mile per-day mileage limit for each house van due to budget constraints. As a result, individuals receiving support from this provider are limited in where and when they can go when they want to leave their homes. The provider suggested multiple houses and clients combine their activities so that they could pool their miles as a strategy for going on longer trips. While this was a mitigating measure, it further limits people’s access to individualized activities and contact with community members who do not have disabilities.

Another house in central Washington had a designated van for the program staff to use for providing transportation, but the individuals supported by that provider
reported that during the hot summer months, they did not enjoy leaving the house because the provider had not repaired the van’s air conditioning. One staff person discouraged DRW from asking one of the men who lived in the home about places he liked to go, explaining that this could agitate the person, who for the past few days had been confined to walking distances from his home because the van driver for his program had been on sick leave.

6. Opportunities for Civic Participation

Opportunities for civic engagement and self-advocacy can also be enfranchising and empowering. For example, Self-Advocacy in Motion is a program in Washington that builds leadership in youths with disabilities.\textsuperscript{51} The project develops leadership, self-advocacy, self-determination, employment skills and disability rights awareness. Youths have learned how to express an opinion, Parliamentary procedure, how a bill becomes a law, legislative issues of importance to youth with disabilities, how to talk to a legislator, ways to practice leadership, and the importance of voting and how to vote.\textsuperscript{52} Developing these skills has led students to engage in substantial civic activities, including: participating in Councils and Boards of Directors, advocating in Washington D.C., finding employment, becoming mentors to other youth, writing to legislators and providing testimony at legislative hearings, and speaking at
events, presentations, and community gatherings. There are many ways people with disabilities can be involved in the general community when self-advocacy and decision-making skills are increased.

DRW found supports for people to participate in civic activities to be especially lacking. For instance, several individuals expressed interest in advocating for their local communities to improve their transportation access. One provider talked about doing advocacy to improve transportation on behalf of clients, but none of the people served by Supported Living providers that we talked to reported ever receiving supports from their providers to voice their concerns to their government leaders or policy makers or connect with advocacy groups. This was not, however, for a lack of opinion on such matters. For example, several individuals voiced disagreements with public policies, such as the kinds of restrictions and policies imposed on them through the Community Protection program. While some Community Protection providers discussed ways in which the provider advocated on behalf of their clients, people did not indicate they received support in self-advocacy to address systemic policies directly impacting their own rights.

Finally, administrators across the state reported having “open door” policies for their clients to talk with them about concerns or issues. One provider talked about parents and guardians serving on the agency's Board of Directors. However, no providers discussed engaging their clients in participating “in policy development and governance” of the program as discussed in the Guidelines to improve individuals’ personal power and choice. In these examples, individuals were at best the object of other people’s advocacy, but they were not empowered to gain the skills or opportunities to be agents of their own advocacy.

If a person is not allowed to make decisions about what to eat for lunch and when, or where to spend a Tuesday evening, it is unclear how or why that person would develop the interest, skills, or confidence to identify and express political preferences about issues extending outside their immediate personal lives.
CONCLUSION AND NEXT STEPS

DRW recommends that individuals, providers, and policy-makers find solutions to address existing barriers to full enfranchisement and continue education efforts to eliminate disempowering practices. This report provides concrete examples of people receiving the types of supports that can either help or inhibit their full enfranchisement, begging questions about how the Supported Living program can be used to systemically enfranchise more people with developmental disabilities.

DRW will be inviting individuals with disabilities, the providers who serve them, and policy makers to participate in focus groups to further explore whether and how increased decision-making skills can lead to greater civic engagement.

Everyday practice in making a variety of choices might be one way to increase capacity and a sense of empowerment to make and express more complex decisions. Conversely, if a person is not allowed to make decisions about what to eat for lunch and when, or where to spend a Tuesday evening, it is unclear how or why that person would develop the interest, skills, or confidence to identify and express political preferences about issues extending outside their immediate personal lives.

If people are to be fully enfranchised, they must be empowered to have and assert opinions about personal as well as political matters. Without daily opportunities and encouragement to make and express choice, individuals are limited in their development of the self-assurance and skills necessary to make and articulate a variety of determinations, including decisions about how and by whom a person wants to be governed.

If given more opportunities to engage with the general community, individuals receiving Supported Living services can have more experiences with the effects of policies and leadership, learn more about the experiences of others, and have more opportunities to share their own circumstances and interests with the outside community. This can encourage people to voice their individual opinions through the electoral and other political processes about issues affecting the community.

In particular, DRW hopes that these discussions with individuals, providers, and policy-makers will help improve the supports provided to people with disabilities and demonstrate growth in empowering people receiving Supported Living services to
experience full enfranchisement between now and the next presidential election in 2016.

7. Service Planning and Delivery Discussion Questions

Individual service planning and delivery should continue to include the person being supported, as well as the case manager and other outside supports, to identify individualized ways each person wants the provider to support habilitation goals, but what specific measures would more consistently and comprehensively implement the six residential guidelines to better support individuals’ enfranchisement? Specifically:

- How should service planning ensure individuals are aware of their voting eligibility?
- What kinds of supports would better help people participate in elections or gain skills to do so in the future?
- How can supported living support individuals in understanding how to make a choice and the nature of voting? Could they use a curriculum?
- What are ways people can access objective and accurate information about upcoming elections, accessible voting options, and the issues or candidates on the ballot?
- How can support services employ financial strategies for securing private internet technology and habilitative supports for developing technology skills to the same extent these plans consider other basic needs and habilitation goals?
- How can service planning and delivery provide for people to have increasing capacity and opportunities to make everyday decisions about their lives, including what and when to eat or drink and how to spend their free time?
- How can service planning and delivery provide for support in self-advocacy and ways to connect individuals with local self-advocacy resources, advocacy events (i.e. Advocacy Day), and opportunities to lobby and educate policy makers about their interests?
- What can Supported Living providers do to assist their clients in learning about, practicing with, and using accessible voting technology?
8. Training Discussion Questions
Staff should of course continue to receive basic training in health and safety requirements, emergency preparedness, mandatory reporting, and individual medical issues to ensure providers are consistently meeting people’s essential health and safety needs. What other training measures would help staff learn how to better support individual empowerment? Specifically:

- What kind of training would best teach how to support individuals’ health and safety without creating rules or using interventions that are more restrictive than what would be acceptable for any other member of the general public, including restricting food choices and enforcing meal schedules?
- What kind of training would best teach how to promote and reinforce confidence in one’s skills and competence without being patronizing or insincere?
- What kind of training would best teach that infantilizing characterizations, baby-talk, descriptions of adults as having a child’s “mental age,” and juvenile nicknames are not acceptable and why?
- What kind of training would best teach that speaking or interpreting for individuals who use verbal communication without the individual’s consent and permission is not acceptable and alternatives ways to support communication?
- What kind of training would best teach that it is not acceptable to interrupt, answer on behalf of an individual, or contradict what an individual is saying, even if it is believed the individual’s statement is untrue or misunderstood?

9. Policy Discussion Questions
The Residential Guidelines established Washington’s general policy for deinstitutionalization and full community integration, but what monitoring and measurement tools would be effective to improve accountability and measure progress? Specifically:

- What policy initiatives would increase access to affordable internet technology and the number of DDA clients who have private access to the internet?
• How should services be monitored and tracked to ensure person is informed about voting eligibility?
• How should supports be monitored and tracked to determine whether services are increasing individual capacity to exercise decision-making?
• How should resources be leveraged to maximize individualized and integrated community activities?
ENDNOTES


5 Id.


8 527 U.S. 581, 601 (1999) (holding that unnecessary segregation of individuals with disabilities may constitute discrimination based on disability because it “perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life” and because “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”)

9 GUIDELINES, supra note 7.


12 See WAC 388-101; CORE WAIVER APPLICATION, supra note 11 at 71; COMMUNITY PROTECTION WAIVER APPLICATION, supra note 11 at 62.

13 See CORE WAIVER APPLICATION and COMMUNITY PROTECTION WAIVER APPLICATION, supra note 11.

14 See WAC 388-101-3460 through 3510; CORE WAIVER APPLICATION, supra note 11 at 68; COMMUNITY PROTECTION WAIVER APPLICATION, supra note 11 at 60. See also GUIDELINES, supra note 7.

15 Limited access to internet services and lack of clarity about voting rights were the only issues discussed in this report that were reported so consistently and frequently across the state that DRW would identify these as potential systemic patterns.

16 For more information on how to get involved in the dialogue, please visit, http://www.disabilityrightswa.org/pizza-politics.

Endnotes, continued

18 Id.

19 According to recent surveys, this likelihood is not unique to people with disabilities. See Linda Lyons, Teens Stay True to Parent’s Political Perspectives, GALLUP (Jan. 5, 2005), http://www.gallup.com/poll/14515/teens-stay-true-parents-political-perspectives.aspx.


24 When last visited, the link to the webpage for voters with a disability was empty, but presumably the Secretary of State’s office has information for voters with disabilities. See OFFICE OF THE SEC’Y OF STATE, https://wei.sos.wa.gov/agency/osos/en/voters/Pages/voters_with_disabilities.aspx (last visited Oct. 17, 2013).


29 In contrast, people living in Residential Habilitation Centers are supported by staff to access and use the internet. See DIV. OF DEVELOPMENTAL DISABILITIES, CLIENT INTERNET ACCESS AT THE RHCs POLICY 6.17 (May 1, 2008) available at http://www.dshs.wa.gov/pdf/adssa/ddd/policies/policy6.17.pdf.


32 Lack of internet access cuts people off from information and services, including jobs, government services, health care, and education and can be marginalizing. See, e.g., Edward Wyatt, Most of the U.S. is Wired, but Millions Aren’t Plugged In, N.Y. TIMES, Aug. 18, 2013, http://www.nytimes.com/2013/08/19/technology/a-push-to-connect-millions-who-live-offline-to-the-internet.html.


34 WAC 388-845-1500.

35 GUIDELINES, supra Note 7 at 5.

36 GUIDELINES, supra Note 7 at 5.

37 GUIDELINES, supra Note 7 at 13.
Endnotes, continued

38 GUIDELINES, supra Note 7 at 5.


40 GUIDELINES, supra Note 7 at 4.

41 GUIDELINES, supra Note 7 at 6.

42 GUIDELINES, supra Note 7 at 8.

43 GUIDELINES, supra Note 7 at 7.

44 Using “mental age” to refer to a person’s disability is no longer considered accurate or appropriate. See Kathy Snow, Developmental Age vs. Chronological Age, DISABILITY IS NATURAL, http://www.disabilityisnatural.com/images/ChronologicalAge.pdf (last visited Oct. 21, 2013).

45 GUIDELINES, supra Note 7 at 9.

46 GUIDELINES, supra Note 7 at 9.

47 Lane v. Kitzhaber, 841 F. Supp. 2d 1199, 1203 (D. Or. 2012)

48 GUIDELINES, supra Note 7 at 9-10.


50 See Disability Advocates, Inc. v. Paterson, 598 F. Supp. 2d 289, 324 (E.D.N.Y. 2009) (citing “evidence that some residents are unfamiliar with public transportation” and that “while homes provide transport services to residents, adult home residents do not have opportunities to learn how to travel by themselves” to support finding that Defendant was failing to provide services in most integrated setting appropriate to individual needs).


52 DISABILITY RIGHTS WASHINGTON, SELF-ADVOCACY IN MOTION 5 (2007).

53 Id. at 7.

54 GUIDELINES, supra Note 7 at 6.

55 DRW understands service planning to include the development of any habilitative support plans, including but not limited to Individual Support Plans (ISP), Individual Instruction and Support Plans (IISP), Positive Behavior Support Plans (PBSP), Cross-system Crisis Plans, Nutrition Plans, and Financial Plans.