Stakeholders’ Priorities Report

Voices of the Community
Town Hall Version

North Los Angeles County Regional Center

March 2018
INTRODUCTION

Between August and December of 2017 almost 1,500 people made time in their lives to participate in the North Los Angeles County Regional Center (NLACRC) Community Needs Assessment Survey. We were very pleased to find that nearly 50% of those responding are people who receive regional center services themselves. Just over 30% are parents or other involved family members with just under 20% of the responders being people who work for people with developmental disabilities as members of our community workforce. Given that the invitation to participate in our survey was done primarily online, through inclusion in the NLACRC Newsletter the volume of returns is astonishing.

This was helped no doubt by our personal presentations and appeals to participate in many public meetings and support groups in our community. Family Focus Resource Center was instrumental in their efforts to facilitate the distribution of our survey throughout our community. We would especially like to thank North LA Regional Center’s Consumer Advisory Committee for helping us identify the initial set of questions and then helping to shape the survey into a People First document. We would like to thank the many service provider organizations who embraced the opportunity to assist the people they serve to reflect on their current life circumstances and then to respond with their true feelings about their interests and service needs. We would like to thank the leadership of the Family Focus Resource Center who helped communicate the importance of this survey to our community and for including us in their very well attended Special Needs Resource Fair where we encouraged participation from all who attended.

That this many people responded to our invitation to talk about their experiences, their challenges and their priorities is both encouraging and sobering. It is encouraging to know that such a large number of people in our community believe it is important to talk with us about issues affecting their lives but it is sobering because it confirms the fact that so many of us face serious obstacles in our efforts to pursue life goals for ourselves and our loved ones. And, it also means that we owe a serious response to each and every person that took the time to engage with us. We do intend to do everything we can to make sure your concerns and your voices are heard by the public officials who you elected to represent you.

COMMUNITY NEEDS ASSESSMENT SURVEY

Survey Methods
The survey was developed by NLACRC in conjunction with their Community and Legislative Educators (Steve Miller and Michelle Heid). The initial set of concerns was developed during meetings with community members such as the NLACRC Board of Trustees, Consumer Advisory Committee, and the NLACRC Self-Advocacy Group. The members of the Consumer Advisory Committee provided particular help in shaping the survey questions to ensure they represent the needs of the community including the issues listed as well as the exact language used in the questions. The intention when creating the survey questions was to meet the needs of everyone in the community to allow wide participation from the disability community including self-advocates, service providers, parents, and family members.

The survey was drafted and shared with focus groups that provided valuable feedback and revisions were made prior to finalizing the survey questions. Questions were worded for each set of target groups (i.e., consumers, parents, and providers). Each set of questions were identical with the exception of modifiers for responder type and the consumer survey added a question about help that was received to fill out the question. Questions were then translated into Spanish and both versions
of the survey for consumers and parents was available online and in a paper version. The provider survey was made available in English online.

**Survey Dissemination**
The North Los Angeles County sent out a link to the electronic survey via several News You Can Use articles between August and December of 2017. A presentation was made to the Vendor Advisory Committee urging their participation in assisting consumers with filling out the paper version of the survey along with encouragement to have their workforce fill out the provider version of the survey online. Presentations were made to many community groups and assistance was provided to parents and consumer during community meetings to complete the survey. Family Focus Resource Center also sent out the survey links via their email newsletter and passed out the survey during their in-person meetings. Attempts were made to ensure the full participation of the community and to reach as many members of the community as possible.

The results of the survey provided rankings on the eleven issues that were discussed during focus groups and other discussions with consumers, parents, and providers in the disability community. Additionally, follow up questions allowed those taking the survey to make text responses to several questions. Text responses were then categorized based on the eleven issues and comments regarding regional center were further categorized into comments related to responsiveness and navigation, funded services, non-funded services, positive comments, and other.

**SURVEY RESPONSES – Rankings and Comments**

**Overall:** total surveys taken 1484

**Survey Responses by Language**

- 86.4% English language survey responses
- 1322 English total responses
- 13.6% Spanish language survey responses
- 162 Spanish total responses

**Surveys by Responder Type**

- 47.6% Consumer responses
- 706 Consumer total responses
- 32.6% Parent responses
- 483 Parent total responses
- 19.9% Provider responses
- 295 Provider total responses
Overall Consumer Rating of Issues (see figure 1 below)

Consumer text responses indicated the most critical issues to them are transportation, employment support, and social and leisure activities. When asked if there are things of concern not listed in the survey consumers made 42 comments about regional center services, 33 regarding social and leisure activities, and 25 about employment support. Supplemental Security Income (SSI) was also rated as a top concern based on comments made. While the survey led to a ranking of issues, the most important information is that all issues were rated as very important by the majority of consumers who took the time to share their opinions.

Consumer comments validated the simple fact that individuals with disabilities want the same things in life that everyone else does. Comments regarding wanting to participate more fully in their community and have full, meaningful life experiences were a theme.

Overall Parent/Family Member Rating of Issues (see figure 2 below)

Parent/family member text responses indicated the most critical issue to them are regional center services where they made the most amount of comments to all three questions regarding regional center services. Comments were primarily related to responsiveness and navigation of regional center services while there were also many comments regarding services funded by regional center. Other comments related to regional center services indicated satisfaction about regional center services and concerns about non-funded services.

Parent/family member text responses indicated concern regarding social and leisure activities, employment support, and housing. Additionally, parents made comments regarding educational support and advocacy. There were also several comments regarding in-home supportive services.
(IHSS) and medical equipment needs. As with consumer responses, the graph indicates that all issues were rated as very important by the majority of parent/family members who took the time to share their opinions.

![Parent/Family Member Rating of Issues](image)

**Providers Top Rated Issues** (see figure 3 below)

Provider text responses indicated the most critical issue to them are regional center services with most comments relating to responsiveness/navigation and funded services. Comments related to ensuring that those they serve are able to access the services and supports they need to live full meaningful lives in the community. Comments were also made regarding transportation, housing, and employment services. As with the other groups, the graph indicates that all issues were rated as very important by the majority of providers who took the time to share their opinions.

Providers also commented regarding provider rates and general funding of services to support individuals with developmental disabilities. Inadequate provider rates were a theme throughout discussions with the regional center provider community during presentations about the survey and in comments made in the survey by providers. Staff shared that they are inadequately paid for the work they do and that raises are not given often to keep up with the high cost of living. We heard from people who provide direct support to individuals with developmental disabilities that they could get another, possibly easier, job and make more money.
VOICES OF THE COMMUNITY

On the following pages is a summary of the voices of the community for each issue which a majority of respondents ranked as very important. This is what was heard when we went out to community groups to facilitate groups filling out the survey. The comments on the survey were thoroughly reviewed and summarized for each issue. We heard that individuals with developmental disabilities want the same things in life that everyone else does. They want to live as full productive members of their community. They are asking for the basics in life that will allow them to live, eat, work, and socialize in their community. They also want to be safe in their homes and in their communities and they want to learn how to better navigate the systems of support and become informed self-advocates.

Parents and family members want these same things for their loved one. They also want services and supports that allow them to care for their family member and provide them with opportunities to have a full life. Parents and family members are also concerned about ensuring services into the future because parents worry about what will happen when they are no longer around to support their loved one. They want to ensure that the services and supports will sustain after they are no longer around to advocate for the services and supports their loved ones need.
PUBLIC TRANSPORTATION

People have told us that it is difficult to get to places around town because buses and ACCESS are not as available or reliable as they would like. How important is improving public transportation for you?

![Survey Results](chart.png)

**Discussion**

The desire to be connected - to share life with others is universal. We live to be members of families and to have friends and social connections. We belong to social groups and we participate in the social, cultural and civic life of the communities in which we live. We also live to be productive – to explore our capabilities and our interests and to prepare ourselves through education and training to join the world of productive employment.

How do adults without private automobile transportation participate in all of these aspects of community life? According to the voices of our community, the answer is with great difficulty. In individual and small group discussions and in the comments submitted to our survey we heard from people that just about all of their adult life activities have to be arranged according to available public transportation.

Can I enroll in a college class? Can I find opportunities to enjoy social and recreational activities where I might meet new people who enjoy the same things and perhaps form friendships? As a job applicant, can I say yes to the question “are you available for evening or weekend hours?”. The answers to all of these questions is entirely dependent upon the availability of public transportation, this is true for paratransit and for fixed bus and train systems.

We heard that when paratransit works just right, it is marvelous. People can get to and from appointments and various community locations safely and economically. But we heard that gaining eligibility for door-to-door paratransit services can be a very difficult process for some. One mother told us she had tried repeatedly to help her adult daughter gain eligibility but could not succeed. She said the problem was her daughter did not have an obvious or observable disability and in some cases probably could ride a fixed route bus, but due to her autism, she would not be safe especially during the evenings or if transfers were required. As more young people with autism or similar conditions transition from high schools to community adulthood the paratransit systems will need to recognize that eligibility determinations may need to adjust to accommodate people who have a lot of capabilities – but have invisible barriers to safe and successful utilization of the regular fixed route bus system.
We heard from people who use paratransit that vehicles can be very late with pick up times both to and from appointments. We heard that ACCESS drivers sometimes don’t stop right in front of a person’s apartment and this causes great stress to get outside in time before the driver leaves. People also shared that they need to schedule rides 24 hours in advance making planning a necessity and spontaneous outings very difficult. While we know that ACCESS is proud of its on-time statistics, to the people who experience these problems this is little consolation.

Additionally, we heard from agencies that offer job development and job coaching that the limitations of public transportation are among the greatest barriers to employment that regional center consumers face. They tell us that job development is often constrained by availability of bus routes that stop near an individual’s home and employers that lie directly along those particular bus lines. They are further constrained by the days and hours that those buses run. Job support agencies also tell us that they are unsure about the ability of ACCESS to provide routine daily and timely transportation to and from work for people who qualify for their services.

Questions for Town Hall Discussion

The solution would include advocating with public officials who have influence over ACCESS and METRO policies and operations. How do we work with public officials to make paratransit eligibility and service delivery more responsive to the needs of people with developmental disabilities?

How do we work with public officials who have influence over METRO routes and schedules to gain a better match between the transportation needs of people with developmental disabilities and METRO services? Given all of the funding recently made available to METRO how can we make sure that buses are available when people need to get to work or to participate in community life?

What roles do city and county public officials play in making these policy decisions? How do people communicate with them and work with them to create and implement meaningful solutions?
AFFORDABLE HOUSING

Are you able to live where you want to? People have shared that finding a good and safe place to live near family and friends is very hard and costs are too high. How important is finding affordable housing for you?

![Pie chart showing consumer responses to the importance of finding affordable housing.]

**Consumer Responses**
- Very Important: 68%
- A Little Important: 16%
- Not Important: 16%

**Parent Responses**
- Very Important: 73%
- A Little Important: 13%
- Not Important: 14%

**Provider Responses**
- Very Important: 73%
- A Little Important: 17%
- Not Important: 10%

**Discussion**

Housing costs in the San Fernando and Santa Clarita Valley areas continue to rise far beyond the reach of people living on low incomes. For people who receive Supplemental Security Income (SSI), their entire monthly check ($910.00) is not enough to rent a studio apartment. Given the population density in our area, the competition for “low cost” housing is so fierce that landlords typically pick among numerous applicants when a vacancy arises. Given the very low-income, high unemployment and absence of credit history that characterizes most adults served by the Regional Center these individuals are at an impossible disadvantage in this competition for scarce housing. The net result of these facts is that housing is out of reach for adults served by regional center unless some form of family or public housing assistance is available to them.

Regional center housing experts tell us that the most effective program is the Section 8 rent subsidy. Unfortunately, the need for these certificates is so great for all low-income residents that the waitlist to fill out an application is currently closed. We heard that even when a regional center consumer is able to apply for a Section 8 rent subsidy, they may be on the waiting list for many years. Without rent subsidies for existing housing, people served by regional centers can only look to public housing and publicly assisted nonprofit housing developments. These developments are very rare and due to recent changes in law restricting certain tax credits, few new projects targeting housing development for regional center eligible adults are being planned.

Together, all of these factors help explain why a large majority of adults served by regional centers continue to live with their now aging parents. In numerous discussions parents told us that they see no future in which their adult children can move out of their parent’s home. While in some cases this may be family preference, for others it represents resignation that no other alternative exists. Several adults in our survey told us they are ready and urgently wish to move into their own adult living arrangements. Consumers shared with us that they may have to live in a situation or neighborhood that is not ideal. Among those who have found the means to move in to their own apartments, several respondents told us that they are located in areas where they do not always feel safe. One said, “I don’t like going outside at night. It’s scary”. 

Page 8 of 25
Regional centers report that many of their clients and families are living in unsafe and or unhealthy conditions. Basic residential services are shrinking. They say they have few options locally for people who need level 2 or 3 ARM type residential services. Aging parents are very worried that there is no appropriate place and support system for their adult children to live. Regional center advocates report that existing licensed group homes are closing faster than new housing options can be found. This creates further difficulty when transitioning individuals from restricted living situations such as developmental centers or institutes for mental disease (IMDs). There is a fear that people will become homeless and very vulnerable.

Questions for Town Hall Discussion

Advocates for affordable housing tell us that while a great deal of new money is being allocated to address the Los Angeles housing crisis, very little is being directed towards the needs of people with developmental disabilities. Advocates say that much more should be done with local, State and Federal authorities to ensure the housing needs of people served by regional centers are addressed by the many new housing initiatives underway. We have to work for breakthroughs to provide more rent subsidies and to find new and creative ways for regional centers to support housing needs.

More specifically, we need to advocate with public officials to increase the supply of Section 8 rent subsidies available and to expand the areas where they can be utilized to more neighborhoods throughout the city.

We also need to advocate with public officials to gain a fair share of the new public funding for affordable housing. There should a representative amount of funding available for new construction and for set-asides for people with disabilities. How do we ensure that individuals with developmental disabilities get fair consideration in the fight for affordable housing?

What roles do City, County, and State officials play in making these public policy decisions? How do people communicate with them and work with them for these solutions?
EMPLOYMENT SUPPORT

Do you have a job you like? People have told us that it is really difficult to get help finding and keeping a good job. How important is employment support to you?

**Consumer Responses**
- Very Important: 67%
- A Little Important: 17%
- Not Important: 16%

**Parent Responses**
- Very Important: 73%
- A Little Important: 14%
- Not Important: 13%

**Provider Responses**
- Very Important: 75%
- A Little Important: 16%
- Not Important: 9%

**Discussion**

You told us that you want the same things for your life that everyone in our society wants. You want to work and earn your own way. You said that work was important to you for several reasons: without a good job and the income it can bring, you do not have the money to live where you want and you don’t have the money it takes to make your own decisions about things you would like to buy or places you would like to go. You said that it was hard to find social activities to do that you can afford. You wish there were more places to go where you could meet people and make friends but it’s very hard to find things that are free and are easy to get to. For so many of these things that make life worthwhile a good job where you could earn enough money and where you could meet people would make all the difference in the world.

While there is not one good source for accurate statistics on the problem, many authorities cite an unemployment rate for adults with developmental disabilities to be above 75%. That means that more than 3 out 4 adults served by the regional center are not working in our community.

Even with such a high rate of unemployment, there are enough local success stories for us to know that – given a fair chance - far more people would be successfully employed. A fair chance for everyone would mean:
- 1) we have a community full of employers actively working to encourage and accommodate job applicants and employees with developmental disabilities and
- 2) all working-age people with developmental disabilities would have access to effective career planning, job training, job placement, and on the job coaching services.

Respondents to our survey tell us we have a lot of work to do. Consumers in our survey said things like "I’ve been referred to Department of Rehabilitation (DOR) and a number of agencies but nobody could really help me because of my physical disabilities”. Family members told us they would love nothing better than for their son to be working – but they do not see anyone with really significant disabilities like their son out in the world working so it does not seem realistic. Agencies who provide employment services told us they were hampered in their ability to develop more jobs and support more people because of high turnover rates among job coaches and job developers. They said that it
would require a big investment in more job developers and more highly qualified job coaches to make a big change in the employment statistics.

When asked about recent State initiatives to increase competitive employment and paid internships, several leading providers responded that they are encouraged, but the roll-out has been slow and uneven. They also said that while there are many great employers out there - much more must be done to educate and encourage our private sector and public-sector employers to open up opportunities for people with developmental disabilities.

We must also note that several consumers told us that they really enjoy their current work at a local subminimum wage workshop, but they are being told it is closing – without a promise that they will get a job right away in the community. For these individuals, it does not appear that their personal preferences have been fully respected.

**Questions for Town Hall Discussion**

How do we work with the regional center and the Departments of Developmental Services and Rehabilitation to speed up the implementation of new State funded programs to increase employment opportunities for people served by regional centers?

How do we work with public officials at all levels of government to encourage public sector hiring of individuals with developmental disabilities? How do we work with public officials to encourage them to promote private sector employment of people with developmental disabilities?

How do we work together to encourage all community employers to recognize the positive contributions that people with developmental disabilities make to the workforce?
SUPPLEMENTAL SECURITY INCOME (SSI)

Do you have enough money to live on? People have shared that SSI is not enough to pay rent and to buy basic things they need to live comfortably. How important is SSI to you?

Consumer Responses

- Very Important: 80%
- A Little Important: 11%
- Not Important: 9%

Parent Responses

- Very Important: 78%
- A Little Important: 11%
- Not Important: 11%

Provider Responses

- Very Important: 81%
- A Little Important: 15%
- Not Important: 4%

Discussion

Many individuals with developmental disabilities qualify for the Social Security Administration’s Supplemental Security Income (SSI) program. SSI provides monthly income for people who qualify and have limited income and resources. In California, the monthly total individual benefit is $910.72 of which $750 is the Federal Benefit Rate and $160.72 is California’s State Supplemental Payment (SSP). This payment is meant to cover basic costs of living, but people shared that much or all of their monthly SSI payments may be used to cover rent. This leaves individuals with developmental disabilities dependent on other resources to put food on the table and cover other basic costs. This economic squeeze makes it very difficult to go out and enjoy social and leisure activities in life.

Through the needs assessment survey many people commented that SSI alone is not enough to live on. When paired with high costs of rent in many areas of the North LA area and difficulty finding employment, the situation becomes even more dire. One person commented that their number one priority is to “encourage the State legislators to increase SSI. It is wrong that people with disabilities have to live in such poverty.”

A family member taking the survey shared that the process of applying for SSI is difficult and suggested that regional center provide more assistance when applying for benefits. Navigation of all the interwoven benefits and programs can be overwhelming for any person, but may be more overwhelming for a family also caring for an individual with a disability or for the person with a disability themselves. Another barrier for parents and individuals is knowing about and understanding the process for applying for benefits and the rules that govern eligibility for all these different systems.

An additional barrier for individuals to receive SSI is having any kind of resources in their name. If parents start college or other savings plans for their children when they are young this may prevent them from accessing SSI in the future. In essence, to be eligible for benefits such as SSI or Medi-Cal a person must remain poor.

Another barrier that is often discussed by parents, caregivers, and individuals with disabilities is that working will reduce their benefit resulting in them not seeking out work opportunities. Advocates for employment state that working is always better for the individual because if they are working, while their benefit may be reduced, they will always have more money each month to live on either just
from work or from a combination of work and their reduced SSI payments. Advocates for employment also cite other benefits of working such as meeting people, social opportunities, and the feeling of contribution that comes from working. There may also be work incentive programs that will allow individuals with developmental disabilities to continue receiving their SSI benefit while working.

Questions for Town Hall Discussion

AB 3200 has been introduced into the State Assembly (Kalra, Reyes, and Thurmond), which would restore small annual cost of living increases to SSI recipients through the State’s Supplemental Payment (SSP). These payments were frozen in 2011. How can we work together to advocate for this bill’s passage?

In 2014, the Federal Achieving a Better Life Experience Act (ABLE Act) was passed which allows eligible individuals and their families to establish savings accounts that do not affect their SSI, Medi-Cal, and other public benefits. In 2015, Governor Brown signed the California ABLE Act into law, but as of 2018 this program has not yet been available to individuals in California. How do we work together to bring this crucial program into existence locally?

Along with SSI there are many public programs that are designed to assist people who are living below the poverty line. Each program has its own rules for eligibility and for determining what kind of assistance might be available depending upon the individual’s situation. How can we work with all of these public agencies to help make these programs more easily understood and available to people served by regional centers?

What role can the regional centers and other advocacy organizations play both advocating with these public agencies and in educating consumers so that they can more successfully utilize all of the programs that are available to them?
REGIONAL CENTER SERVICES

Do you have the services you need? People have told us they have difficulties communicating with their service coordinator or getting the services they need. How important is improving regional center services to you?

![Survey Results]

**Discussion**

The topic of regional center services was ranked among the highest priorities and received the highest number of comments. The importance of the regional center to our community is clear and makes perfect sense. Under the Lanterman Act, regional centers are placed squarely in the center of our State’s commitment to meet the needs of people with developmental disabilities and their families.

Here is the mission statement of the NLACRC:

*North Los Angeles County Regional Center, with integrity and transparency, provides lifelong partnerships and planning to persons with developmental disabilities by promoting their civil and personal rights, providing comprehensive information, advocating in cooperation with consumers, promoting and providing high quality services, and supporting the full participation of consumers and families in all aspects of community life.*

The comments of people responding to our survey touched on every aspect of this mission. Many expressed appreciation for the support and guidance they have received over the years. The majority of comments though, expressed a desire to see the NLACRC improve on the performance of their mission. Many of the comments expressed a desire to have phone calls and emails returned more promptly. For families looking for answers and information, delays in receiving callbacks or email responses, is not a minor irritation, but rather leaves people waiting and unable to move forward to resolve a problem or better understand a situation.

Several people commented that they wished they could get more information from regional center about available programs and services. These comments included observations that the best information seems to be available from other parents rather than directly from regional center or their service coordinators. The thirst for more information was expressed repeatedly. Respondents said they want help to understand all of the options for services that are available to them and they want help to sort-out which options are the best fit for their specific situation. Several parents or family members wrote comments addressing a desire for regional center to provide more information – even parent classes or workshops that would help them do a better job of preparing their child for
adulthood. They asked for classes in preparing for independent living and for transition from school services to adult services. One particular comment from a father who participated in a discussion group summed up the desire for more information and understanding this way: “I didn’t go to college to prepare for raising a child with a disability, but now I need to know so much. Not just about my son, but about this whole system – all the different players who have their own rules, eligibility, and paperwork. I need to know it all to take care of my son.”

There were also comments expressing a desire for the regional center to be more active in advocating for the services they need directly through regional center and on behalf of their school-age child’s special education needs. On this note, several survey respondents said they want to feel that the regional center is fighting for them – not with them.

Questions for Town Hall Discussion

How can the regional center engage its community in a dialog concerning expectations for responsiveness to consumer and family requests for call backs, email contacts, and for substantive answers to requests for information and assistance?

Does the regional center currently conduct consumer satisfaction surveys to determine the extent to which they are meeting their consumers’ expectations for responsiveness? If not how can we work together to create opportunities for meaningful feedback?

The NLACRC mission statement describes the center’s commitment to providing comprehensive information and advocacy in cooperation with the people it serves. How do consumers and family members engage with the regional center to work towards the highest possible fulfillment of this commitment? It is fair to say that each of the 25,000 people served by the regional center is a unique individual with his or her own personal circumstances and service needs. How can the NLACRC best utilize all of its available resources to ensure that each person it serves receives the information, planning assistance, and advocacy he or she needs to fulfill his or her personal goals as described in the center’s mission statement? How can community advocates work to help regional centers reduce caseload ratios in order for service coordinators to realize the mission of NLACRC?
HEALTHCARE

How easy is it for you to take care of medical or dental problems? People have shared concern over receiving good healthcare through Medi-Cal or other insurance providers. They may have difficulty finding doctors or getting appointments. How important is healthcare for you?

Discussion

Through the survey our community shared that healthcare is very important to them. Medicaid, called Medi-Cal in California, is a health insurance program for low-income or disabled individuals, which is jointly funded by the State and Federal Government. Most regional center consumers are eligible for Medi-Cal through the Home and Community Based Services Waiver, which “waives” certain Medicaid rules allowing states to provide services to people with developmental disabilities in ways that are not available to other people. Once a person becomes eligible for Medi-Cal they also have to navigate the different Managed Care Plans (MCPs) in their county or fee-for-service Medi-Cal.

While many individuals with developmental disabilities are eligible for Medi-Cal or Medicare we heard that the process of applying can be very confusing and time consuming. We also heard that once eligible it can be difficult to find doctors and dentists who are accepting new patients and it may take a long time to get an appointment even with established doctors. It also may be very difficult to find doctors, dentists, or specialists that are close to their home making it difficult to access these services.

One family member shared that Medi-Cal services are not the best and that consumers with Medi-Cal get the “left over” doctors, dentists, and specialists. This may be due to many healthcare professionals only taking a small percentage of Medi-Cal patients due to low reimbursement rates. This leaves Medi-Cal patients with difficulty finding and getting appointments with doctors, dentists, and specialists in a timely manner. Many parents and family members expressed concern with finding good dental care especially when sedation is needed. They also shared that getting regional center funding assistance for this can be difficult if they cannot find a dentist in their area. One parent shared that while they live in the Antelope Valley they have to see a dentist in Tarzana making it an all-day trip for the family.

Some consumers may have private insurance that must be accessed for some services prior to Medi-Cal reimbursement or regional center funding. This often leaves families with high deductibles and co-payments that must be paid out-of-pocket to get the necessary services their children require. One
parent reported that her son’s health insurance is expensive and she often finds herself deciding between food on the table or her son’s therapy and services.

We also know that the medical needs of our community can be complicated and that it may be difficult to access specialists that can understand and meet the needs of individuals with developmental disabilities whether the consumer has Medi-Cal, private health coverage, or Medicare. Several comments were made about the time that it takes to get the medical attention that people in our community need. Parents and family members expressed concern, but consumers stated that they would like help quicker especially when they are in pain.

Questions for Town Hall Discussion

Healthcare is such an important and almost overwhelming issue to tackle. What can be done locally to expand the number of doctors who accept new Medi-Cal patients? What can be done to make more medical specialties available throughout the County?

How do we work with local public officials to improve access to care for people served by regional centers?

What roles do local and State officials play in making these public policy decisions? How do people communicate with them and work with them for these solutions?

There is also a wide-spread sense of fear that healthcare and related human services are threatened by proposed Federal budget and Medicaid policy initiatives. How can people work together at the local level to advocate for a strong safety net of healthcare and human services?
SOCIAL AND LEISURE ACTIVITIES

Enjoying life with friends. People have said that finding fun activities to do in the community for recreation and to meet friends is hard. How important are social and leisure activities for you?

**Discussion**

Walk past a local park any weekend or summer day and you will hear the shouts and laughter of children playing together and competing in youth sports leagues. Drive by any park in the evening and you will see and hear soccer and softball games organized by parks and recreation departments. For most of the children and adults in our community there are too many leisure time and social recreational opportunities to choose from.

Unfortunately, people responding to our survey tell us this is not the case for children and adults with developmental disabilities. Parents and family members of regional center eligible children said their strongest wish was that they could find some places in their local neighborhood where their children could go to play and to make friends. Parents and family members who primarily speak Spanish listed this desire for local social and recreational opportunities among their most urgent wishes and needs. Adults told us they wish they had places to go to meet people, have fun and make friends. One said, “I wish I could go somewhere to dance and sing, that would be fun”. One parent said, “It’s great that my son has an apartment of his own now – but as far as I can tell he has no friends and he doesn’t really have anywhere to go where he fits in or where he is welcomed. It feels to me like he’s isolated”.

To be sure, there are organizations that provide social and recreational activities for kids and adults with disabilities. But people responding to the survey tell us that the number and location of organizations who provide organized activities for free or for very low cost and are easily accessible by public transportation is much smaller. Organized sports and social – recreational activities for non-English speakers with disabilities seem to be even less available.

Many people told us that when the regional center lost their ability to fund local social and recreational programs, their children’s worlds became much smaller and less rich. They describe the loss of summer camps and recreational opportunities as very hurtful. It appears that these lost services have not been made up through local parks and recreation programs, local Boys and Girls Clubs, YMCAs and other generic community resources. The expressed desire of most individuals with disabilities, and their families is to feel welcomed and incorporated into community-wide social, cultural, and recreational activities. Unfortunately, the majority of people responding to this survey believe this is not currently the case in our area.
Questions for Town Hall Discussion

People with disabilities live as members of every neighborhood. We want to work toward a community in which every park, cultural, and civic meeting place is as open and inviting to community members with disabilities as they are to anyone else.

How can people work with local City and County officials to build greater recognition of the needs and the rights of community members with disabilities to be fully included in community programs? How can we work with public officials to make sure reasonable accommodations and outreach activities to the disability community are considered in the planning and operation of all social, recreational, cultural, and civic activities?

What roles do City officials play in making these public policy decisions? How do people communicate with them and work with them for these solutions?

Advocates are also working hard to persuade the Governor to lift the ban on regional center funded camps and social recreational programs. The ban was imposed during the deep financial recession ten years ago and is no longer financially justified. How do we go about communicating our needs and our priorities to the Governor?
ADA COMMUNITY ACCESSIBILITY

Are buildings and community services accessible? People have told us that there are times when they are unable to go places or participate in community activities because of accessibility barriers. How important is ADA compliance in the community for you?

Discussion

In 2015 then Attorney General Loretta E. Lynch commemorated the Americans with Disabilities Act’s (ADA’s) 25th anniversary with these words, “By prohibiting discrimination and ensuring opportunity, the ADA has opened doors and brought dreams within reach...Indeed, the true power and promise of the ADA lies in its ability to empower individuals with disabilities to dream bigger, and to enable them to pursue their own visions of the American dream”.

She concluded the celebration with this challenge: “right here today, we must redouble our efforts and recommit ourselves to confronting the lingering obstacles that prevent people with disabilities from fulfilling their personal and professional potential – from discrimination, to inaccessibility, to restrictive education and employment opportunities”.

In survey responses and conversations people told us that we do, indeed, have a long way to go before the promise of the ADA is fully realized in our community. We heard from one women, “There is a park just down the street that I would love to visit but there isn’t a curb cut on the corners so I can’t get there”. “Sometimes I hear people having fun and I wish I could too”. Another woman said, “I have serious back and leg problems, I had to stand in a long line at the bank yesterday. Finally, I just had to give up and leave because I couldn’t stand up any longer”. In a telephone interview, a self-advocate related the frustration of having to telephone her sister for help because she was trapped in a hotel restroom that lacked an accessible doorway. Bringing the issue close to home, NLACRC arranged to furnish a ramp at a local hotel for a speaker when it was discovered that the hotel was not equipped to accommodate public presentations by people who use wheelchairs.

In addition to physical barriers the ADA prohibits discrimination in employment and discrimination in access to full participation in all areas of community life. In this light, the many comments in our survey regarding a lack of community social – recreational programs may also represent concerns that local public agencies are not fully meeting ADA requirements for accommodations to promote full inclusion.

One of the greatest obstacles to more full compliance with the ADA is the fact that, outside of building permit requirements, enforcement is complaint driven. If people are not aware of the specifics of the law, they do not know they are being discriminated against. Additionally, the burden is often on the
individual to prove the complaint and to propose the remedy. For someone served by the regional center – this burden can be overwhelming. As challenging as it may be now to enforce the promises of the ADA, there are current efforts in Congress to make enforcement even more difficult.

**Questions for Town Hall Discussion**

While individual voices combating discrimination may be hard to hear, the collective voices of our community are even harder to ignore. Further advocacy education focusing on the importance of full implementation of the ADA is necessary.

How do we effectively and powerfully communicate the importance of active enforcement of all city, county, state and federal laws that help make our community truly accessible to people with disabilities?

What roles do local and State officials play in making these public policy decisions?

How can the regional center play an active advocacy role and collaborate with other groups who are working to protect and improve ADA rights?
SELF-ADVOCACY, LEGAL RIGHTS EDUCATION AND ADVOCACY

Do you know what services are available to you? People have said that it can be difficult to navigate the system of supports (regional center, DOR, school district) and being a good advocate is difficult. How important is knowing what services could be available to help you?

![Survey Response Pie Charts]

**Consumer Responses**
- 74% Very Important
- 17% A Little Important
- 9% Not Important

**Parent Responses**
- 87% Very Important
- 3% A Little Important
- 10% Not Important

**Provider Responses**
- 85% Very Important
- 12% A Little Important
- 3% Not Important

**Discussion**

There are so many laws and regulations governing the agencies that control access to crucial services for people with disabilities. How could anyone understand all the rules and regulations under the Lanterman Act, the Individuals with Disabilities Education Act (IDEA), Medi-Cal, Supplemental Security Income (SSI/SSP), In-Home Supportive Services (IHSS), Americans with Disabilities Act (ADA), Department of Rehabilitation (DOR), regional centers, school districts, and private insurance providers? The truth is nobody could navigate all of these systems without help.

The majority of responders to the survey recognized their lack of knowledge in these areas and expressed their need for more help than they presently receive. The majority of comments focused on difficulties understanding and advocating within the special education and regional center systems. This makes sense given the prominent role schools play for children and the abrupt transition that takes place to regional center services on or before a person’s twenty-second birthday. Consumers and family members expressed frustration with how difficult it was to find accurate and understandable information about their rights to services. Responders to our survey expressed the desire both for education to help them navigate the system themselves and for expert advocacy assistance when they feel they are “up against the authorities” and need to “fight for their rights to services.”

As one father put it, “I didn’t go to college to prepare for having a child with disabilities, but there is so much I have to know now.” Another parent said, “It’s exhausting and so stressful trying to advocate for your child, I often feel overwhelmed. I could really use more support.” Another said, “we need more support to advocate for our kids at school. Maybe there could be classes to teach us how to advocate and negotiate the IEP process with the schools”. Another suggested there should be classes for parents when their child approaches adulthood, “We need classes to understand everything – all the services that an adult might need.” People who receive services expressed the same concern. One young man said, “I know we have rights but I don’t really know what they are. Maybe we need some lawyers to tell us what our rights are.”
Questions for Town Hall Discussion

It is true that there are numerous bureaucracies that an individual and or family must navigate in order to gain the assistance that he or she needs and is entitled to by law. It is also true that there are several agencies who receive public funding specifically to provide information, education and direct advocacy assistance to individuals and families who need help to understand and effectively utilize the systems and services they are entitled to under the law.

How do we engage with all of these advocacy organizations to help them better publicize their responsibilities and availabilities to provide advocacy services to people who are unaware of their existence and or their responsibilities to provide these services?

How do agencies including regional centers, Family Resource Centers (FRCs), Disability Rights California (DRC), the State Council on Development Disabilities (SCDD), and others currently fulfill their advocacy responsibilities? How can we engage with them to determine where there are gaps in currently available advocacy services and how those gaps can be filled?
SAFETY AND SECURITY

Do you worry about your safety at home or in the community? People have shared that they worry about their safety at home, when going out in the community, or online. There may not be enough information about protecting yourself. How important is safety and security to you?

<table>
<thead>
<tr>
<th>Consumer Responses</th>
<th>Parent Responses</th>
<th>Provider Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Important</td>
<td>A Little Important</td>
<td>Not Important</td>
</tr>
<tr>
<td>82%</td>
<td>76%</td>
<td>72%</td>
</tr>
<tr>
<td>9%</td>
<td>16%</td>
<td>8%</td>
</tr>
<tr>
<td>9%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Discussion**

National statistics confirm that people with developmental disabilities are at a higher risk than others of becoming crime victims and targets of abuse, exploitation and bullying. While this does not mean that people served by regional centers need to live in constant fear, it does give credence to survey responders who listed concern for personal safety and security as very important.

Adults served by the regional center offered comments such as, “I wish I could live in a safer place” and “I worry about people stealing from me”. Parents expressed concern that their children could be bullied at school. Another parent voiced concern about the screening and supervision of employees working in direct support roles.

Family members also expressed concerns for the adequacy of training that law enforcement and other public safety personnel receive in order to serve and protect community members with developmental disabilities. One parent referred to television news coverage of a young disabled man who was shot at because the police mistook the toy truck he was holding for a gun. He said, “he could very easily have been my son”. When taken all together, the survey paints a picture of a disability community that is worried about its personal safety and security.

**Questions for Town Hall Discussion**

As much as we may wish that these concerns were unwarranted, the facts and statistics make it clear that they are. The only reasonable response to these risks is a commitment by all responsible agencies to continuously improve their awareness of the vulnerabilities people with disabilities and to continuously improve their community safety practices based upon the most current research and best practices. Police, fire fighters, bus drivers and others should have the best possible training regarding community members with disabilities and how to help them especially in times of difficulty, stress and vulnerability.

How do we work with public officials to make sure that all appropriate agencies continuously train their personnel in the current best practices in meeting the personal safety concerns of disabled community members?
The regional center plays a prominent role in working to ensure the personal safety of the individuals they serve. They have relationships with local law enforcement and public safety agencies. It provides information and expertise to these agencies regarding the needs of people with developmental disabilities. It may be reassuring to members of the community for the center to publish information from time to time about these interagency collaborations. How would we work with the regional center to further promote programs and activities that address the personal safety concerns of the people they serve?

CONCLUSIONS

Through the Needs Assessment Survey we heard from many self-advocates, parents, family members, and providers. We heard that when things are going well families and individuals with disabilities have the support they need to live meaningful lives in their community. When good relationships exist with regional center and other support agencies people with developmental disabilities and their families feel like they have partners to help them reach their goals. But when this is not the case, people can feel overwhelmed and that they face many challenges and a bewildering maze of “systems” to navigate on their own.

Perhaps the most important and least surprising fact gleaned from the survey is that all issues were rated as very important by the majority of consumers, parents/family members, and providers who took the time to share their opinions. This means that in our community we have a lot of work to do to ensure that people with developmental disabilities have the supports and services they need to live good lives in communities that include and value them. We have work to do to ensure that people have good places to live, the healthcare they need and opportunities to work and lift themselves out of poverty. We have work to do to protect our community safety net so that never again will parents be haunted by the ultimate nightmare: “what will become of my child when I am gone?”

The good news is that, thanks to the hard work of previous generations of advocates and enlightened elected officials so much of our foundation already exists. The good news is that there currently are many committed advocates and public officials working hard to protect and reinforce the support systems people need.

If our community is ready and willing to work together to address the challenges that they identified in this survey, then there is every reason to believe that, collectively we can bring about the positive changes that people with developmental disabilities need and deserve.