

I Get to Live My Life



*Consumers, Service Providers
and Regional Center Staff
Talk about Supported Living*

Adapted from the
1997-1998 SLS Survey



California Department of Developmental Services
Community Services Division
Program Services Branch
Services and Supports Section

Preface

Between December 1997 and March 1998, Department of Developmental Services staff conducted face-to-face and telephone interviews with dozens of consumers, regional center staff, and service providers all over California. The purpose was to learn more about how Supported Living Service (SLS) was being implemented across the state, directly from the people closest to it. This booklet is a selected, edited and adapted compilation of thoughts and experiences expressed in the course of that 1997-1998 SLS Survey. These comments of consumers, regional center staff, and vendors of services reveal, as cold statistics never can, how the promise of supported living is becoming a transforming, inspiring force in the daily lives of real people.

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“I get to live my life,”

a consumer responds when asked what it means to live in his own home. In six short simple words, the answer sums up what Supported Living Service (SLS) is about.

As one of several different living arrangement options the Department of Developmental Services offers to meet the varied needs and preferences of adult consumers, Supported Living Service helps people with developmental disabilities live in their very own homes in the community. Although it has been around for years, and even though living in one's own home and being in charge of one's life is taken for granted by most people without disabilities, somehow SLS is still a new and growing idea as we enter the new millennium.

It can be a bit scary, too, because it means being self-responsible and more open to what life may bring. But with friends and family offering – and receiving – support and love, with knowing use of the community's resources, and with other needed services and supports, living in one's own home can mean a happier, more fulfilling life for many consumers.

This booklet presents the testimony of people all over California who, from their own experience, know how true this is.

 I like living independently much more than living in the residential facility. I have much more freedom. I didn't like the rules at the facility. (*Consumer*)

 A young woman with dual diagnosis was in a group home, with services costing \$10,000 monthly. She was self-injurious. Now she gets 100 hours of support monthly, has her own cleaning business, and pays taxes. She now lives in a two-bedroom apartment with a roommate. She needs her space and gets it in her own home. (*Provider*)

 A woman I worked with had been in a foster home and was extremely depressed, and couldn't hold a job. Now she has a job and lives on her own with just a few supports. (*Regional Center Staff*)

 I'm glad I got this place. (*Consumer*)

 My son's made great progress taking care of himself. He's learned life skills, such as cooking and planning meals. My son is in charge of making one meal. He does planning, shopping and cooking (with assistance). My son now does his own laundry and rides the bus. He is getting to know people in stores. My son has a lot more confidence and self-pride. (*Parent Provider*)

 Two consumers were placed in a developmental center when they were young. Then they moved to a board and care home for fifteen years. They met with their case manager and one of them asked about employment services. She was laughed at, but finally jobs were found for both of them. Later, both lost their jobs to downsizing. So they

found new jobs – not supported employment but real jobs. We wanted them to get a home because they were getting older. We helped them set up a savings plan, and three years later they bought a home. One retires in three years, and her goal is to make sure they have their house paid off. They are good citizens, active in their community, civic partners, and registered voters. (*Regional Center Staff*)

 I think that helping us live in our own home is the most wonderful thing. Because of this opportunity to live in the community, people with disabilities are able to lead normal lives, despite having disabilities. (*Consumer*)

 We once visited a client who was living in an unhealthy situation. His clothes all smelled of urine. He was not eating properly. The attendants were running the show. We got him new furniture, and now after two years in supported living he is very happy. He goes places now and does things in the community. He is living in a clean home in a good neighborhood. This was a huge turnaround for him. (*Provider*)

 I recall a consumer who was always reluctant to make changes in her life. She decided to go into an assisted apartment living arrangement. Later she expressed a desire not to be “locked in” – which is how she felt – at the apartment. Now she is in supported living and told the service coordinator that she's so happy now and has more confidence in herself than before. (*Regional Center Staff*)

 While I have been in supported living, there has been a dramatic change in the medications that I take. I am

now taking one-half of the medications that I had previously taken. (*Consumer*)

⊗ There were three sisters, now in their 30s and 40s, living in a board and care home, who were very frightened of the outside world. All three moved into an apartment together and were terrified at first. We did a lot of role playing with them to help get them comfortable living in the community outside the group home environment. The change took about three years to fully kick in. Now there is a complete metamorphosis, and they now use all the community resources. (*Provider*)

⊗ One consumer wanted to continue living in the city where he worked. His whole family helped him plan the move to his own place, and there was a lot of support from his church also. His supported living agency found a condominium and a roommate who was the owner. Everything just came together. (*Regional Center Staff*)

⊗ Yes, it is wonderful. (*Consumer*)

⊗ A woman with two kids had a history of abuse and lived in a group home. She lost her kids because of a drug problem. She started by getting Independent Living Service, then Supported Living Service. The drug problem is now gone, and she has good follow-through with any problems that come up. The agency has gotten to know her well and now she has a strong circle of support that the agency put together. It is a big factor in her improvement. (*Provider*)

⊗ Some of our best successes have been Supported Living Service agencies who care and are committed to working with consumers who have complex challenges, such as significant medical needs or mental health issues. We have vendors who work with these consumers so they are empowered with opportunities for choice. These vendors give consumers respect and dignity. This is not a common trait of all providers. Among consumers there is a tremendous response of success to the respectful treatment they have received. (*Regional Center Staff*)

⊗ I think I have the best living arrangement for me at this time. (*Consumer*)

⊗ The most exciting moments have been seeing consumers move from a very restrictive life style to their very own home. Also, it is exciting to see people that had been labeled as having challenging behaviors completely change, and seeing these behaviors disappear completely. (*Provider*)

⊗ One of my consumers has lived a pretty amazing life since going into supported living — it suits her. (*Regional Center Staff*)

⊗ I like supported living, but sometimes my back-up assistants aren't properly trained. (*Consumer*)

⊗ Five of the consumers we are giving services to have fired support staff – demonstrating their control. (*Provider*)

 I see supported living working well for persons who are chronically kicked out of residential facilities and for deflections from the developmental centers. Supported living seems to be the most stable living situation for these people. *(Regional Center Staff)*

 Supported living is better than being in an ICF. I like making choices and being responsible for myself. *(Consumer)*

 A young man with mental problems, and who was always highly medicated, was in and out of group homes. No one thought he could live independently because of the level of his difficulties. He has been in supported living now for one and a half years and lives alone. We give him services to help him keep his house clean and manage his money. This has been very successful. The difference is that now he is in control of his home and life. His family is very involved, which has helped make things so successful. *(Provider)*

 I recall two people from the developmental center who were regarded as “holy terrors.” They are new to supported living now. They have support staff, and just being able to stay in the community would make this arrangement a success. One has been able to access the community a lot and hangs out at a coffee house. I have to praise this agency. *(Regional Center Staff)*

 It’s really neat to be living in my own place. I used to live in a group home, but it wasn’t what I wanted. *(Consumer)*

 In 1996, we helped a man from the developmental center get an apartment and a roommate. He was in his mid-30s and had been living at the developmental center a long time. He wanted a lot of privacy instead. Now he lives alone. Things are going well. There has been great improvement in his behavior. He used to set fires. But he stopped doing this after getting into his own apartment. We think the improvement is due to his now “having his space” in his own place, and not having so many conflicts with others. *(Provider)*

 A consumer had resided all of her life in state institutions, and later at four different residential homes. She has resided for the past two years in her own apartment, cooking, budgeting, and taking care of it. She loves her own place. *(Regional Center Staff)*

 Yes, I like this program. It is much better than a group home. *(Consumer)*

 We had a couple who met and lived in the developmental center for years. Then they moved into the community and got married. We helped this couple move into their own home and provided supports to them. The husband passed away. But his wife is so thankful that they got to live together in the community, and says that this was the best time in both their lives. *(Provider)*

 Some consumers that haven’t done well in a group home have been very successful in supported living. Challenging behaviors have decreased. Because of this we have been able to avoid sending consumers back to the developmental center. *(Regional Center Staff)*

 I'm a happy man. I don't like to be bothered by other people, but I really like to help other people. *(Consumer)*

 We have a consumer who has no arms or legs and who has psychological problems too. She has challenging needs, but we all feel that her supported living arrangement has improved her quality of life. She's very bright, but her medical needs cause problems. I saw her happy to be interacting with people, going on picnics and to the beach with friends. She doesn't feel tied down by her condition. We found her very difficult to work with at first, but eventually she calmed down and overcame many difficulties. She is freer to do things she wasn't able to do before. *(Provider)*

 Every one of the supported living arrangements are successes. We keep working with our consumer and the Supported Living Service agency until the supported living arrangement succeeds. *(Regional Center Staff)*

 Supported living is the best thing for people like me. It makes it so that I can make up my program and have control of my time. That is the best thing. Before, I was under everyone's control and had to do a program that was not for me. A lot of times I got upset and got into trouble. With supported living, I can take care of my needs when I have to. If I need to be alone, then I can be alone without interaction. I can choose when I want to go out and have company and visit my friends. Before, I could not have a good life like now. It was horrible for me. I can have a life with supported living. That is why I like supported living. Because I get to live my life. *(Consumer)*

 I met this 67-year-old lady that had to move, but she did not want to go into a care home. She wanted her own place. I helped her find one and she is doing great! Her spirits are very high. She says she has finally started her "real" life. *(Provider)*

 A consumer had lived most of her life in out-of-home placement settings, ranging from foster care to a developmental center. She has lived in her own place for three years. It has been the happiest time she's ever had in her life. *(Regional Center Staff)*

 I am very independent and I like to make choices. *(Consumer)*

 I remember a consumer who liked to eat out constantly, and so was always broke. This consumer wanted to visit his girlfriend who lived in Texas. Well, his support staff worked with him on ways to save money. They started working with him on cooking foods he liked at home, so he started eating at home instead of spending on meals outside. The consumer saved up \$700 and was able to make the arrangements to go visit his girlfriend in Texas. *(Provider)*

 A consumer, who didn't have good judgment and was involved with the criminal justice system, wanted supported living service. The family is very involved, and his employer is very involved. Now, a year later, he is doing great, with no incidents in the community since his supported living began. *(Regional Center Staff)*

 Yes – I really like supported living. I would also like a girlfriend. *(Consumer)*

❄️ A 78-year-old consumer living in a developmental center had been asking to live on her own for over two years. Now she lives in her own place and is doing great. We use a Senior Center nurse, subsidized housing, and she gets items for her apartment from a senior recycling program. Her favorite pastime is going to the beach. And the cost of her monthly supported living services is less than the developmental center costs. (*Provider*)

❄️ There is a woman with small children whose sister-in-law was going to court to take the kids away. Child Protective Services was also involved. We got her connected with a Supported Living Service agency which assisted her with court appearances. She changed apartments and got into parenting classes. She has since gotten her children back. (*Regional Center Staff*)

❄️ I like it. I know my neighbors. I want to go to Las Vegas again, and go on a roller coaster, and fly in a plane, and go to Magic Mountain, and go on a water slide. And I want a family feast, and to learn to ride the bus by myself. (*Consumer*)

❄️ A married couple moved from a Board and Care setting into their own apartment. They had a baby boy after moving into the apartment and he is doing well. Today, the family is doing great. (*Provider*)

❄️ There is a consumer with severe cerebral palsy, but no mental retardation, who has been very successful in supported living. Without it, this consumer would have to be living in an institution. (*Regional Center Staff*)

❄️ I just think it's a good way to have my own privacy. Someone is always asking you to do this or that in a group home. When you have your own house, you can do whatever you want. I have a lot of people to talk to, and I started a club at the college. (*Consumer*)

❄️ We have a consumer from a family with many problems, with violent and verbal abuse going on. At the beginning, this consumer was quick-tempered and uncooperative. We got him into his own place about one-and-a-half to two years ago. Getting him into his own place made the difference because he got away from the bad environment he was in. Now he gets to be in charge of making decisions in his own life. He "grew" and stabilized and became responsible, and developed his goals. He got a driver's license. He is in his early 20s. His self-worth and self-esteem are now high, and he is content with how he is living. (*Provider*)

❄️ We helped a consumer with lots of behavior problems move out of the developmental center into a very expensive supported living arrangement. The consumer needed a 2:1 care ratio. But it was still less expensive than the developmental center. (*Regional Center Staff*)

❄️ I like supported living. I want it to keep going. If that program were not here, we would be lost. We would have to live in a group home. I lived in one before and I didn't like it. (*Consumer*)

❄️ There is a man in his late 40s who lived in group homes. It looked like he'd never be living independently because of his poor hygiene and constant

need to be prompted. He was uncooperative. Now he lives with a roommate in his own place. He is active in his church, and now does his hygiene on his own, without prompting. He is involved in community recreation. He gets twenty hours of service each week for the last two years. He has friends who are not paid friends, and he has had big successes due to living on his own. *(Provider)*

❄️ There was one consumer who came out of the developmental center. First he went to a group home, and then he went into supported living. He is living a life that he never thought would be possible for him. *(Regional Center Staff)*

❄️ They treat me real good, and when I don't understand something, they help me with that too. *(Consumer)*

❄️ A 68-year-old male developmental center client had a history of aggressive behavior and property destruction. We tried a licensed facility placement, but it didn't work well. We moved him into a three-bedroom home which he rented. He was initially destructive, for the first three months. Then he slowly started bonding with the staff from the agency. Until recently he has had a very steady staff, with little turnover. His behaviors decreased drastically. He now ventures out into the community more. We believe that the change is due to him living in his own home, rather than in a licensed facility. *(Provider)*

❄️ I guess one of the best success stories for me was to see two consumers, who had spent most of their lives living in the state developmental centers, now live in their own apartment. Both of them are very happy with their

living arrangement and have been very successful in their new lifestyle. They have the key to their apartment and truly feel empowered. *(Regional Center Staff)*

❄️ I do not know what I would have done without supported living. It is great. *(Consumer)*

❄️ It is crucial that SL services continue. It is the best thing to come along in a long time. The constituent community needs to be willing to take the risk of increasing supported living for consumers. We need to continue to make supported living better. We owe it to the consumers. *(Provider)*

❄️ A consumer who wasn't sure supported living would work for him is now so happy with his life. He was very fearful before. He has matured and grown tremendously since he's been getting supported living. *(Regional Center Staff)*

❄️ I couldn't make it without it. Having the support and feeling safe is so important to me. Before supported living, I only had IHSS. I could not go back to that. *(Consumer)*

❄️ I feel very positive about supported living. My daughter has always been considered a very complicated case. Supported living has allowed her to grow. It is customized for each person. The services that were available for her before supported living never seemed to work well for her. Now she has a very positive, happy life. We are thrilled to see how she lives now. *(Parent Provider)*

⊗ The consumer had very poor judgment and was on parole for a sex offense. He needed to have more support than Independent Living Service provided to live independently. He had very committed parents who wanted the program to succeed. Now he has his own home, with a roommate, a good job, and a good social circle. *(Regional Center Staff)*

⊗ I would recommend supported living to anyone who wants to live on their own. It is a great program, and I love it. *(Consumer)*

⊗ Supported Living really is the best alternative that I have seen in my son's lifetime for persons with developmental disabilities. He has responsible and caring support staff that enjoy working with him. He has a great living situation, and I am proud of it. *(Parent Provider)*

⊗ We have two 18-year-old consumers who have made excellent progress. One of the consumers had some challenging behaviors which have decreased dramatically. Their support people have been very creative in helping them live in their home. The consumers have a color code for helping them make a sandwich and to do personal tasks such as laundry. *(Regional Center Staff)*

⊗ Everything seems good now. Before I lived in this apartment, I lived in another apartment with a different roommate. Things were not so good then, but are much better now. *(Consumer)*

⊗ It's a great program. It's especially neat when families do not like group homes. They really light up when

they are allowed to create a program to give their adult child a better life. Families help to hire people in supported living, as opposed to not having a say in group homes. *(Provider)*

⊗ Our typical success story goes like this: it is a consumer who has been living in a group home for years and whose parents are very comfortable with the group home. When the family gives us a chance to develop a supported living arrangement, there is often a dramatic change in their attitude. They start to see the really positive self-esteem changes that occur in the consumer as he or she succeeds in their own home. *(Regional Center Staff)*

⊗ I feel great. No one tells me what to do. I like that. *(Consumer)*

⊗ It can change lives. It forces creativity and individualism. It produces growth and blossoming of the person. Everyone needs more education on supported living. It's a worthwhile and tremendously inspiring program. *(Provider)*

⊗ There's the case of one consumer whose former psychologist claimed would never make it in supported living because of behavior outbursts and self injurious behaviors. Now the same consumer has been so successful that his most serious negative behaviors have all but disappeared. *(Regional Center Staff)*

⊗ I love it here! It feels nice to live in our own place. *(Consumer)*

 Supported living is a breath of fresh air and freedom. It may be a consumer's only chance to live a good life. *(Provider)*

 This consumer lived in several residential care facilities before moving to her own place with support from a Supported Living Service provider. She was in crisis, and there were no other licensed homes that would accept her. Also, her mother/conservator insisted on trying SLS. It took nine months to stabilize her behaviors, with 2:1 staffing needed during some days and also 24-hour supervision. For two years now she has been successful in her own apartment, with decreasing services and supports. *(Regional Center Staff)*

 It is fun to be responsible for yourself. *(Consumer)*

 Supported living is the wave of the future for consumers. We need to include consumers who are parents in this future. Supported living has helped us in dealing with the legal system in our effort to keep the family together. We value what supported living has added to the system. *(Provider)*

 There was an abusive, vandalizing, non-verbal autistic consumer from a developmental center. It was a very rough experience for the first month in his own apartment. But for several years now, the consumer has not destroyed the couch and is now cooperative with female staff. At first the consumer was on Haldol, but now has had only two doses in six months. The reason for the change, we believe, is his being in his own apartment, and without the stress of

having to live and accommodate to other consumers. *(Regional Center Staff)*



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For More Information...

The full name of the Department of Developmental Service's regulations is: *California Code of Regulations, Title 17. Public Health, Division 2. Health and Welfare Agency - Department of Developmental Services Regulations.*

The Supported Living Service regulations are available through the Internet at <http://www.dds.ca.gov>. A printed copy of the official regulations may be purchased from: *Barclays Law Publishers, 400 Oyster Point Boulevard, PO Box 3066, South San Francisco, CA 94080. Phone: 415-244-6611.*

For more information on supported living or additional copies of this booklet:

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