WAYS TO INCREASE INDEPENDENCE: SUPPORTED LIVING

A Presentation by

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WHAT THIS TRAINING WILL COVER

- Summary of my background
- Landmarks of becoming independent
- The process for receiving (S)upported (L)iving (S)ervices and the Regional Center
- Some advice on judging SLS agencies
- Brief mention of IHSS
- Description and assessment of strengths and weaknesses of various living situations including
 - Group homes
 - 24/7 SLS
 - Lesser support SLS situations
- Q+A

ABOUT ME

- Studied psychology at Oberlin College, graduated with B.A. in 1998
- Graduated from Life Chiropractic College West with D.C. in 2005
- Worked at Lifehouse 2006-2013 as Supported Living Manager, and joined the Senior Management Team in 2011
- Became ILS Coordinator at ICS in 2013, Living Skills Director in 2016
- Graduated with an M.A. in marriage and family therapy from Northcentral University in 2019
- Currently a Registered Associate Marriage and Family Therapist supervised by Bj Brown MFC, license #30551 at Seeds of Awareness in Petaluma

HOW WILL MY CHILD BECOME INDEPENDENT?

HOW AND WHEN DID YOU BECOME INDEPENDENT?

Think back...

YOUR FIRST TRIP TO THE MALL WITHOUT YOUR PARENTS...

YOUR FIRST JOB...

YOUR FIRST ROMANTIC RELATIONSHIP...

GOING TO COLLEGE...

YOUR FIRST BILL...

YOUR FIRST APARTMENT...

WHAT ARE SOME OF THE KEY FEATURES IN THESE SITUATIONS?

- Being on your own
- Building confidence in steps over many years
- Engaging in activities against your parent's wishes
- Suffering the consequences of your decisions
- Actually having to face real difficulties in a variety of realms

THERE ARE SUPPORTS THAT CAN HELP YOUR CHILD ACHIEVE SOME OF THESE MILESTONES IN SOME FORM...

- Life Skills supports
- Prevocational supports
- Vocational supports

YOUR FIRST APARTMENT...

WHAT HAVE I SEEN IN 15 YEARS IN SUPPORTED LIVING SERVICES?

UNDERSTANDING SUPPORTED LIVING

Request Regional
Center to visit
residential programs

- Qualify for RC services
- Additional services, like ILS and SLS, available at age 18

Find residential program that is best suited

- Make the case for the program to the team
- Get agreement from the team that the program(s) is/are appropriate and able to be funded

Wait for an opening/Find an apartment or home

- · Wait to be notified about an opening
- Visit the particular apartment/home
- Assess fit and make decision on moving forward
- If renting or buying, get agreement from agency and RC to provide support on given date

NOTES ON REGIONAL CENTERS

- Regional Centers provide lifelong services to individuals with qualifying disabilities
- Unlike the schools, RC's are set up to coordinate the services, and this is their primary role
 - Less contentious relationship
 - Typically, you don't need to fight as much for services
- They do have procedural rules, which can impact flexibility around supports

GENERAL PRINCIPLES IN CHOOSING AN AGENCY

- The qualities of the organization as a whole will impact your communication, how heard you feel, and the general framework within which services are provided
- The qualities of the managers and supervisors will be very important on how responsive the agency is and how thoroughly they respond when issues come up
- The cleanliness and feel of the homes is one important measure of the professionalism of the agency – though it does depend on the amount of staffing and if the homes are owned by the agency or not
- The qualities of the staff at the home will be most important to your child's life and most critical to service delivery

THINGS TO OBSERVE IN STAFF

- How do the staff interact with the residents?
- How do the staff treat you?
- Can you speak with residents and their families?
- Are they on their phones at all and if so, for what reason?
- Does the home appear to belong to the residents or to the staff?
- Do the residents participate in independent living activities, such as cooking, cleaning, to the best of their abilities, etc.?

TYPES OF STAFFING SET-UPS

- Within residential support situations, there are a variety of potential living situations with varying amounts of support
- I will discuss the variety of community living situations that I have had experience with: Group homes and a variety of Supported Living situations

VARIOUS LIVING SITUATIONS

- Group homes
- 24/7 Supported Living
- Overnight+ Supported Living
- Everyday SLS supports in a home/condo
- Supported (SLS) Apartment Group Living Situations
- Supported Living with 1x, 2x, or 3x weekly meetings

WHAT ABOUT IHSS?

- IHSS stands for (I)n (H)ome (S)upport (S)ervices
- It is a County based service for individuals with Medi-Cal that have trouble caring for themselves
- A social worker from the County will complete the assessment
- People in group homes do not receive this service, as far as I know
- People who enter Supported Living Services are required to get an assessment
- IHSS services are for providing support for activities of daily living, NOT instruction
 - They will do laundry, house cleaning, cooking, picking up medications, picking up groceries, and personal care
- Some SLS agencies provide these services through their own workers
- Other times an IHSS worker is hired who shares the care

AGAIN, VARIOUS LIVING SITUATIONS

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WHAT IS A GROUP HOME?

- A home, most typically 6 beds, in a minimum of 3 bedrooms
- The agency owns the home
- The home is licensed
- Staff are present all the time
- There are a variety of rules to be followed:
 - Residents have no access to medications
 - Residents have no access to money
 - Residents do not have access to the kitchen
 - Residents cannot be in the home alone

GROUP HOME LEVELS

- Group homes work on a level system,
- The level determines which have to do with the rules, types of supports, level of supports (1:2, 1:3, etc.) the clients in the home need
- This will be discussed briefly at the end of the presentation if there are any questions about it
- This is not my area of expertise, as I have worked in and with agencies with group homes, and worked with those clients, but not managed or supervised them

GROUP HOME

POTENTIAL UPSIDE

- Home is a community
- Chance to work on cooking and other living skills once or twice per week
- Safety and security are paramount and homes are licensed
- Can stop access to medications, food, etc.
 very easily it is not the person's home
- Affordable

POTENTIAL DOWNSIDE

- No choice over housemates/roommates
- Often must share a small bedroom
- Not allowed in home when staff are not present
- No chance for independence around finances or medications
- Must leave the house if everyone goes on outing with staff

STORY: GROUP HOME

- Group homes, when well run, can be excellent
- Here is a story which highlights some of the shortcomings
- I worked with an older man with a mild intellectual disability.
- Lived in group home for over 20 years
- Many behavioral issues
 - Repeatedly would lose temper, at least monthly
 - Bang his head on the wall, make holes
 - Never assaulted anyone, but was very intimidating
- Moved into a situation with his own bedroom, had one incident in 2 years
- In speaking to former staff, issues were almost always related to getting along with others

WHAT IS AN SLS HOME WITH 24/7 SUPPORTS?

- A home, condo, or 1-2-3 bedroom apartment
- The individual rents or owns the home
- Typically one staff is present all the time
- The SLS staff rotate, and usually in a variation of the following pattern: 3-11pm,
 11pm-9am (overnight), and weekends
- There may be a manager and/or assistant manager, normally attending to several similar homes
- The IPP/ISP plans for the individuals determine the types of services provided, including whether the person can be alone in the house or not

SLS HOME WITH 24/7 SUPPORTS

POTENTIAL UPSIDE

- Safety staff can always be supervising
- Flexibility individuals can have a plan that allows for being alone in house
- Individualization around meals, routines and goals can happen (theoretically)
- May have choice in housemates
- Individuals have their own bedroom

POTENTIAL DOWNSIDE

- Staff are always present, making it difficult for individuals to learn skills and take responsibility
- Often individualization is difficult as one staff is working long shifts with 2-4 individuals
- Often staff lose motivation on long shifts
- House may appear that it belongs to the staff, not the residents

STORY: MIXED 24/7 HOME

- Worked in a home with 3 individuals, all with different functional capabilities
- They had moved from group homes or from family home
- These individuals included someone who was minimally verbal, and two individuals who were in the moderate range for intellectual disability
- One person needed staff at all times, one could be alone if staff was close by, one could be alone for up to 2 hours with staff out of the area
- Because we had a staff in the general area, this allowed these clients much more freedom to stay or go, participate in outings or not, etc.
- It worked surprisingly well, though none of these 3 appear to be a good match
- A memorable situation here was that an individual was on a medication for years and I wondered about this. Asked previous group home, it was in their records that this was the medication. Spoke to doctor about what med was for (anxiety), and asked that it be stopped. Got stopped, and the client had no problems.
- Had another example of a person we thought had Hep B because it was in the record. We eventually had him tested, no Hep B.

WHAT IS AN SLS HOME WITH OVERNIGHT+ SOME DAY SUPPORTS?

- A home, condo, or 1-2-3 bedroom apartment
- The individual rents or owns the home
- There is staff present overnight, usually 9pm-9am or some variation
- The hours during the day would be at times of higher need, like dinner, breakfast, etc., such as 4-6pm every night
- Weekends might vary between a few hours to many hours of day support
- There may be a manager and/or assistant manager, normally attending to several similar homes
- The IPP/ISP plans for the individuals determine the types of services provided,

SLS HOME WITH OVERNIGHT AND SOME DAY SUPPORTS

POTENTIAL UPSIDE

- Safety there is still a lot of support
- Flexibility there is an allowance for time alone, shows confidence in the individual
- Individualization around meals, routines and goals can happen (in reality)
- May have choice in housemates

POTENTIAL DOWNSIDE

- Individuals are without staff some time every day
- High staff presence can mean less ownership over home/responsibilities

STORY: HOME WITH OVERNIGHTS AND VARYING LEVELS OF SUPPORT

- A home with an individual who was identified as needing overnight plus daily supports, and two individuals who are quite independent
- We have been able to provide a worker who works with the client that needs more supports, for about 18 hours per week
- This client gets instruction and training for laundry, cleaning routines, cooking 5 days a week
- The other clients have two meetings per week with their own instructors
- Overnight supports are there every night, which provides safety for everyone, but as the clients get along with each other well, the more capable clients can provide the safety for the less capable client in the home
- At one point we had an argument that couldn't be resolved between two tenants in the home, and the police came...at that point we had to put in more supports

WHAT IS AN SLS HOME WITH EVERY DAY SUPPORTS?

- A home, condo, or 1-2-3 bedroom apartment
- The individual rents or owns the home
- There is staff present on a daily basis for some amount of time
- Weekends might vary between one hour to many hours of day support
- There may be a manager and/or assistant manager, normally attending to a large number of similar homes
- The IPP/ISP plans for the individuals determine the types of services provided

SLS HOME WITH EVERY DAY SUPPORTS

POTENTIAL UPSIDE

- Safety there are eyes on the person daily
- Flexibility there is an allowance for time alone, shows confidence in the individual
- Individualization can happen (easily)
- Allows for support around a key area (like medications or dinners) on a daily basis
- May have choice in housemates

POTENTIAL DOWNSIDE

- Individuals are without staff most of the time every day and overnight
- High staff presence can mean less ownership over home/responsibilities
- Individuals could have people spend the night without staff knowledge
- In general, increased risk

STORY: HOME WITHOUT OVERNIGHTS AND VARYING LEVELS OF SUPPORTS

- Three bedroom home with sometimes 2, sometimes 3 women
- Home was left by family to daughter, who has master bedroom
- Additional two bedrooms were rented, tenants were provided by the agency
- Each person had their own staff during the days
 - One person had 2 meetings per week for 3 hours each
 - One person had 3 meetings per week of 2 hours each
 - One person had 2 meetings per week for 4 hours each
- House meetings were about every 2 months, or as issues arose
- Sometimes the women hung out together
- Fights were about storage space, messiness

WHAT IS A SUPPORTED (SLS) APARTMENT GROUP LIVING SITUATION?

- An apartment complex in which several disabled individuals have apartments (e.g. a 25 unit building and there are 4-8 disabled individuals in apartments)
- The individual rents their own apartment (maybe with an apartment mate)
- There is staff present on a daily basis (for anywhere from 4-12 hours per day) for some amount of time, who visits with each person
- There may be a manager and/or assistant manager who lives onsite in one of the apartments, who can respond to emergencies
- The IPP/ISP plans for the individuals determine the types of services provided

SUPPORTED (SLS) APARTMENT GROUP LIVING SITUATION

POTENTIAL UPSIDE

- Safety there are eyes on the person daily
- Ownership as there are no staff always present in the home
- Individualization can happen (easily)
- Allows for support around a key area (like medications or dinners) on a daily basis
- There is a community close by

POTENTIAL DOWNSIDE

- Individuals are without staff most of the time every day and overnight
- Individuals could have people spend the night without staff knowledge
- In general, increased risk, though things get discovered quickly

STORY: SUPPORTED APARTMENTS

- Worked in a program, with 2 buildings, and approximately 7 apartments and 7-8 clients living there; complex was for people over 55 years
- We had to apply for openings when we had new potential tenants, they accepted Section 8
- One staff was there 7am-3pm and one staff from 3pm-7pm weekdays, and weekends was 12-5pm
- Clients were friendly with each other, some close, some more distant
- Each person has a day for more support
- Daily check-ins for everyone in morning and evening
- One person we helped with dinner every night, some with medications morning and evening, etc.
- Sometimes we had overnights in place, and this shift could help with others if need be

STORY: SUPPORTED APARTMENTS

• We had a client whose family insisted that he could not use a stove independently, but never provided background as to why. We grudgingly agreed to remove electric burners when he was alone. The guy actually loved to cook, so we used to encourage him to cook when we were around. One time I put on the burners, for him to make popcorn on the stove in a small pot. I then got called out to check on another client living across the hall. When I returned, he was sitting on his couch watching TV while happily eating popcorn. I noticed that the pot was sitting on the carpet next to him. I went to pick it up, and it had burned through the carpet.

WHAT IS A SUPPORTED LIVING SITUATION WITH IX, 2X, OR 3X WEEKLY MEETINGS?

- A home, condo, or 1-2-3 bedroom apartment
- The individual rents or owns the home
- There is staff present I-3 days a week to meet with the individual
- There may be a manager and/or assistant manager, normally attending to a large number of similar homes
- The IPP/ISP plans for the individuals determine the types of services provided

WHAT IS A SUPPORTED LIVING SITUATION WITH IX, 2X, OR 3X WEEKLY MEETINGS?

POTENTIAL UPSIDE

- Freedom to live an adult life
- Ownership of the living situation as staff are only there a small fraction of the time
- Individualization can happen with work on goals
- Allows for support around a key area (like medications or dinners) a few days a week

POTENTIAL DOWNSIDE

- Individuals are without staff most of the time every day and overnight
- If the person tends to "find" trouble, this situation may not work well, as it may be much easier for individuals to hide things

STORY: MARRIED COUPLE

- Older couple, married; husband worked, wife was retired
- Family helped them with a small home
- Needed daily supports around medications (less than 2 hours per day)
- Very routine based
- Their life was very similar to any married couple

GROUP HOME LEVELS

- Level I: Limited care and supervision for persons with self-care skills and no behavior problems.
- Level 2: Care, supervision, and incidental training for persons with some self-care skills and no major behavior problems.
- Level 3: Care, supervision, and ongoing training for persons with significant deficits in self-help skills, and/or some limitations in physical coordination and mobility, and/or disruptive or self-injurious behavior.
- Level 4: Care, supervision, and professionally supervised training for persons with deficits in self-help skills, and/or severe impairment in physical coordination and mobility, and/or severely disruptive or self-injurious behavior. Service Level 4 is subdivided into Levels 4A through 4I, in which staffing levels are increased to correspond to the escalating severity of disability levels.

IT IS POSSIBLE TO START OFF WITH MORE SUPPORTS AND MOVE TOWARDS LESS SUPPORTS

- Such a situation can be ideal for a variety of reasons
 - Allows for gradual growth
 - Allows for piece of mind as parents, as it is a slower process
- Such a situation can be difficult to make happen for a variety of reasons
 - Agencies may not have multiple situations for individuals to "graduate" through, so moving may involve change in agency and staff
 - If the whole community is built in an area, moving can cause loss of community

IT IS HELPFUL TO HAVE A PLAN...

- It is helpful to work with an advocate, knowledgeable therapist, or agency that provides supported living in many settings
- Even one to two meetings can be very helpful!
- If you work with an agency to get help, be cautious, as they may have a vested interest in steering your child towards a certain program
- Make sure the person you speak to (if from an agency) is more of a ground level person, like a manager that works with clients
- Higher level people at agencies often are not aware of potential service mismatches

IN SUMMARY

- Moving out is a big step
- Think about how to evaluate providers
- Understand the options
- As safety increases, freedom often decreases
- As support increases, motivation often decreases
- Safety is often more important initially
- More freedom (when possible) may be more important to growth in the long run
- Seek out someone to help you evaluate options

Q+A