



Forum on Helping people move from Developmental Centers

2/2/04

Facilitated by Michael Smull

Sponsored by Connections for Information and
Resources on Community Living (CIRCL)

Co-sponsored by California Supported Living Network (CSLN)



CIRCL Forum on Helping people move from Developmental Centers

Connections for Information and Resources on Community Living (CIRCL) Presents

***A CIRCL Focus Group To Continue the Learning And Sharing
About Moving People Into Their Own Communities***

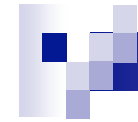
**Co-sponsored by California Supported Living Network (CSLN)
February 2nd, 2004**

**Facilitated by Michael Smull, President
The Learning Community on Essential Lifestyle Planning**

Contact Information:

**Michael Smull
Support Development Associates
3245 Harness Creek Road
Annapolis, MD 21403
(410) 626-2707 or (fax) 626-2708
www.elpnet.net
mwsnull@cs.com**

**Claudia Bolton, CIRCL
4171 Starkes Grade Road
Placerville, CA 95667-9204
(530) 644-6653
www.allenshea.com/CIRCL/CIRCL.html
cbolton@northstarsls.org**



CIRCL Forum on Helping people move from Developmental Centers

Introduction

From time to time, Connections for Information and Resources on Community Living (CIRCL) sponsors community forums and workshops on different aspects of supported living services. In February, 2004, CIRCL (with funding from the Department of Developmental Services) co-sponsored with the California Supported Living Network (CSLN) a forum on the issues and challenges involved in helping people move from developmental centers into their own homes and communities. Michael Smull, internationally known authority on person-centered thinking and planning, was asked to facilitate the forum. This document is a summary of that day.

Purpose

- To first look at what we have collectively learned about helping people move from developmental centers to community settings and what we have learned about helping them have lives in their communities.
- Then to use what we have learned to develop recommendations about improving our efforts.

Michael's job was to help participants uncover what has gone well, what hasn't gone so well, and what we might do differently (e.g., assessments, transitions, community resources, staff training, system supports) to help individuals move out of institutions and into their own communities

Stakeholder Groups Invited

Invitations were sent out statewide to individuals and organizations that represented:

- People who have moved
- Families of people who have moved
- Planners
- Regional center
- Agency staff
- Advocates
- Developmental Center staff
- Regional Resource Development Project staff

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The Agenda

To accomplish the above purpose, the day was divided into 3 parts (a more detailed description can be found in Appendix A) -

- Part 1. What have our experiences been to date, what has worked and not worked?
- Part 2. Looking for themes
- Part 3. What can be strengthened and changed?

The day was 'wrapped up' by discussing strategies for each theme and talking about what each individual would commit to do *tomorrow*.





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Summary of Themes (Activity 2)

Once everyone had an initial opportunity to post about what has worked and what has not worked (see Appendix B for that 'raw' material by stakeholder group), groups worked to developed themes in each area by what has and what has not worked.

What has worked in identifying people who will leave next?

- Learning about individual preferences through person-centered planning
- Planning the move through meetings and visits with everyone involved in the circle of support
- Identifying individuals that want to move or must move because of court orders

What hasn't worked?

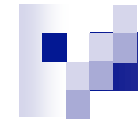
- Using the readiness model to identify people who are leaving developmental centers
- Lack of information about people who are leaving developmental centers
- Parental and others (e.g., developmental center staff) fears and objections about moving from developmental center

What has worked in planning with people before they leave?

- Creating a sense of positive energy and changing the inertia through the planning process before someone moves
- Plans that are in sufficient detail to describe someone's preferences, needs and desires
- A strong commitment to the individual and visits to the community
- Interagency partnerships
- Information to individuals about their living options in the community

What hasn't worked?

- Multi-agency process is a barrier to leaving developmental centers
- Lack of funding and other resources in planning for a move from a developmental center
- The person is not included in the planning meetings
- Time limitations for planning a move
- People at planning meetings don't have enough information about the individual or the resources
- Lack of choice when looking at alternative living options



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What has worked in figuring out where to live?

- Identifying and building relationships and a support team when looking at possibilities for where to live

What has worked in developing individual budgets?

- Make sure that the team has input
- Budgets need to be complete and detailed, with flexibility and independence as core planning values

What hasn't worked in developing individual budgets?

- Cost caps, lack of financial resources, and inflexibility are barriers

What has worked in making that first month after leaving a successful one?

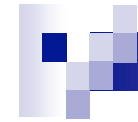
- Partnerships, commitment, staff training and knowledge of the individual make the first month after moving a successful time
- Forgiving each other and not blaming other team members if things get tough in the first month after leaving
- Holding a team meeting within the first month after leaving
- Making the right individual/staff match makes the first month after leaving successful

What hasn't worked?

- Getting timely health, medical, mental health service access, and staff training
- Not being able to identify and qualify for needed generic resources in a timely way after leaving
- Staff and individuals understanding the emotional aspects of moving
- Unexpected changes in individual needs or resources within the first month of leaving

What has worked in helping people stay out of developmental centers?

- Community services individually designed for the person
- Professionals teaming, sharing and collaborating
- Building, maintaining, bridging, nurturing family and friends
- Think about the characteristics of people who have been referred for admission to a D.C.



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What has not worked?

- Lack of needed services (e.g., mental health crisis placements)
- Placement is some times a convenience to regional center
- Courts ordering placement when it's inappropriate
- Poor collaboration between regional centers and Regional Resource Development Projects

What worked for people who returned or did not return to developmental centers after 3 months?

- Knowing individuals well enough to successfully support them
- Valid assessments for better support
- Follow up and commitment throughout the process

What did not work?

- Developmental center staff understanding of individual support needs
- Insufficient planning and supports
- Overregulation by all of the agencies involved in the move
- Narrow knowledge of the individual by support staff
- No emotional support for the individual

What worked about people who were identified to move and haven't?

- The planning process is positive and gives hope and determination
- Establishing that people will be safe wherever they live

What did not work?

- Community capacity wasn't adequate
- Money, training and personnel issues
- Family concerns over changes in relative's life
- No support for SLS as a viable option and listening to what people want and need
- A sense of frustration, lack of empowerment by individuals who are moving
- Developmental centers are uncertain about adequate support in the community
- Legal issues



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In general, what worked?

- Respecting individual rights in supported living
- Honoring individual choice
- Teamwork among all members of the circle of support (staff, family, community)
- Staffing based on good matches with individuals
- Resources and training are adequate

In general, what did not work

- Misrepresentation of individuals and
- Administration concerns
- Individual concerns
- Lack of reliable emergency support
- Abuse of power by staff in offering direction to the individual
- Fear of failure

In the 2nd thru 6th month after people moved, what worked?

- Continuous staff training for support staff
- Individual choice continues to be honored
- Clinical support is in place
- Flexibility and problem solving by all team members
- Trust and commitment by all team members
- Follow up visits to make sure that planning has been successful and needed changes are made

In the 2nd thru 6th month after people move, what did not work

- Family understanding
- Planning glitches
- Lack of time to adapt to the change



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- Resource gaps

Other things that need to be said and listened to

- A mutual understanding of terms (e.g., ILS, SLS, LRE, 24 hour support)
- Cost and availability of adequate housing
- Family history is not always known or available
- A shared philosophy with common values
- Additional training (e.g., mental health, safety, risk, boundaries)
- Forensic issues of individuals involved with the justice system



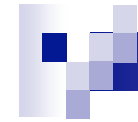
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Things That Are Working and Could Be Strengthened (Activity 3)

- Staff Development
- Capacity of community support agencies
- Collaboration
- Planning and assessment
- Community resources
- Individual choice and training
- System change
- Self-determinaton

Things That Are Not Working and Could Be Changed

- Person-centered focus
- Funding
- Housing
- Partnerships
- Training
- Crisis intervention
- Support services
- Changes in philosophy
- Benefits planning



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Things That We Can Do Something About

Things That We Can Do Something About - Self-Determination

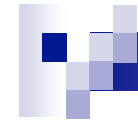
- More education and awareness on a statewide basis
- Merge and collaborate with self-advocacy networks
- Involvement by individuals using services and supports in all levels of policy-making
- Start to address concerns expressed by service providers and regional centers
- Identify and promote cost savings potential

Things That We Can Do Something About - Community Resources

- Create locally referenced listings of generic resources for all areas of the state
- Develop an online library of generic service listings
- Develop contingency resource plans (e.g., health, mental health) for individuals in transition from developmental centers
- Create and deliver (e.g., online) systematic training materials on accessing generic community services

Things That We Can Do Something About - Assessments

- Train a cadre of statewide planners and contract with local vendors for assessments prior to the transition plan
- Inform assessment funding agencies that good plans take an average of 30 hours
- Use a variety of approaches in assessing individual needs and preferences (e.g., Essential Lifestyle Planning, Dream Deck) for people who do and do not use words to communicate
- Assessors should have greater access to individuals and those who support them while still living at developmental centers (e.g., visits to potential living options)
- Make sure that assessments are multidisciplinary (e.g., nurses, occupational and physical therapists) as needed



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Things That We Can Do Something About - Staff Development

- Develop an interagency network for staff training, employment, mentoring
- Promote low-cost training opportunities so that more staff can participate
- Provide information and training on all agencies and services
- Get better at listening to individuals and their families and staff regarding ways to improve services and supports through training and education

Things That We Can Do Something About - Political Barriers

- Create political pressure by educating the legislature on how proposed cuts will result in greater costs to the service system
- Educate individuals, families, and support staff about current threats to funding and possible outcomes (e.g., loss of health care, increased use of congregate care, loss of jobs)
- Educate individuals and families about self-determination
- Educate and act (e.g., letters, rallies, community forums, develop and disseminate position statements)

Things That We Can Do Something About - Mind Sets

- Use the media to promote positive examples of community inclusion
- Continue to facilitate the introduction of individuals with disabilities to the community

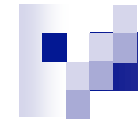
Things That We Can Do Something About - Roles and Responsibilities

- Team members need to be held accountable for follow-through on transition plans
- Develop a 'case' responsible person for overall authority to complete the transition plan
- Roles and responsibilities need to be clearly identified on the transition plan
- Develop a systematic planning outline and stick to it, for example:
 - Draft plan that includes actions needed, dates for completion, person or persons responsible



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- Assessment of individual needs and preferences
- Funding for plan is identified and secured
- Opposition and barriers to transition are identified and anticipated
- Transition time line is developed
- All stakeholders meet to discuss plan
- Regional Center secures all necessary community supports and funding (e.g., Medi-Cal)
- Generic resources are identified and approached as needed
- Community support staff are trained
- Alternatives for living and other types of supports are presented to the individual



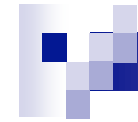
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Examples of What we will do tomorrow?

- Try to find out more about what 'happy' looks like for the people I support
- Work harder to advocate for personal preferences
- Focus on building partnerships in the teamwork needed to help people move
- Make sure that we are using person-centered thinking in addition to planning
- Stay focused on personal preferences
- Make sure that everyone is on the same page when looking at *moving out* plans
- Reconnect with people I have helped planned with and make sure that follow-through has happened
- Work on defining roles and responsibilities in the *moving out* process
- Learn more about being a systems navigator
- Get more knowledgeable about interviewing to make sure personal preferences have been documented



Appendix A
Detailed Agenda



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Part 1. What have our experiences been to date, what has worked and not worked?

The first part consisted of posting a series of questions and giving everyone a number of different colored post-it notes to respond to the questions. Each color post-it represented a different “stakeholder group.” Since a number of these important groups were under-represented, participants were asked to answer those questions from the perspective of the other groups. However, participants were asked to answer a question from another perspective only when they felt reasonably certain what that person might say if able to attend. The stakeholder groups that we represented were:

People who have moved (or are designated to move and haven’t)

- Families members of people who have moved (or are or were designated to move and haven’t)
- Planners (the people who actually wrote the plan that was used to help someone move)
- Regional center staff (other than the planner)
- Support agency staff
- Advocates
- Developmental Center staff
- Regional Resource Development Project staff

In looking at what has worked and not worked, participants were asked to think about:

- Identifying people who will leave “next”?
- Planning with people before they leave?
- Using plans to figure out where, how, and with whom people should live?
- Using plans to develop budgets?
- Helping people in their transition?
- The 1st month after people move
- The 2nd thru 6th month after people move
- Individuals that were identified to move and haven’t
- Individuals who have moved and returned to Developmental Centers within 3 months
- Individuals who have moved and returned to Developmental Centers after 6 months
- In general



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Part 2. Looking for themes

After everyone had a chance to respond to all of the questions, participants were divided into groups to look for themes. The process for that activity was:

- Look for those items that are identical in content or very similar. Move the post-its so that they are together.
- Look at those items that remain. For each one, ask the group if this is a new grouping or could the item go in an existing group. If an existing group which one? If it **is** new put it by itself. Go through all of the items this way. Keep in mind that single items may get “company” as you go and that groups that were initially created may need to be split into new groups.
- Look at each group. How would you describe what that group says or implies in a few words? What is the theme that the group represents?
- If there is a question about what any item means see if the person who wrote it is available to explain. If there is disagreement over where an item goes and the person who wrote it is available she or he has the final say.
- As each group completes its work its members go around and read what the other groups have done. If there is disagreement with what another group has done all of participants briefly discuss it to see if there is consensus. If there is no consensus, both interpretations are noted.

Part 3. What can be strengthened and changed?

In the third activity, participants were asked to look at all of the themes that were developed and then go back into work groups based on those major themes. Each group was asked to make suggestions as follows:

- What is working that could be strengthened?
- What isn't working that could be changed?
- Who needs to participate?
- What needs to happen



Appendix B¹
What Has and What Has Not Worked
By Stakeholder Group

¹ This information has not been altered in any way. It was typed up from post-its as is with grammar and terminology in tact.

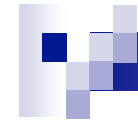


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**Focus Group February 2, 2004
Information Directly From The Post It Notes - No Editing Or Rewriting Was Done
Organized By The Topic Area From The Wall Paper Prepared At The Session**

Identifying People Who Will Leave Next - What Has Worked

- ❑ It would work if we assume that all can be served in the community
- ❑ Selecting people who want to move out
- ❑ Identify people with court orders to move out
- ❑ Assuming that ALL will move during meetings with families and DC staff
- ❑ Question: If not, Why?
- ❑ The DC teams making recommendations
- ❑ Learning about consumers through person centered planning
- ❑ Knowing that he/she will succeed and prosper from a change of environment
- ❑ Helping the person speak up so the DC staff will listen to their desire to move
- ❑ Forgiving past behavior
- ❑ "get to know me", "nothing about me without me", "remember it's my life"
- ❑ Take time to get to know the person - don't rely solely on a referral packet
- ❑ Planning the move through meeting and visits with the Circle of Support
- ❑ Regional center team process to share and consider what is known about each individual
- ❑ Regional center support to take as much time as needed to develop a plan
- ❑ Helpful RRDP
- ❑ Great Planning
- ❑ Team approach
- ❑ Continue to try when it's rough
- ❑ Multiple visits with the person who is moving



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Identifying People Who Will Leave Next - What Has Not Worked

Lack of Consumer Information

- ❑ Individuals (in DC) don't get the information they need to understand the full variety of community living arrangements
- ❑ Individual don't get to visit different types of living arrangements
- ❑ Going through the planning process and then nothing happens and no one explains why
- ❑ People are asked if they want to move before they are given a meaningful chance to see and understand community options
- ❑ There seems to be some difficulty educating people about supported living. It remains a mystery for many folks in the D.C. and their families
- ❑ I don't consider SLS because I have been given the impression it is too expensive and that family and the individual will have to pay for it.

Readiness Model

- ❑ Individuals thinking: I am not "ready to leave" until my behavior is good (i.e., gold level)
- ❑ Individual absorbs staff views that they are not "ready"
- ❑ Use of Point System or Readiness criteria
- ❑ The idea that people are not "ready" to move because of behavior, weight, medical, point and level systems
- ❑ DC using a point and level system to decide who can move
- ❑ Making my son or daughter meet unrealistic goals or standards that we do not apply to ourselves
- ❑ Expecting him/her to be "cured" of their diagnosis

Parents have objections and fears

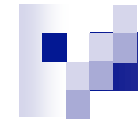
- ❑ When people aren't moved because of parent's objections
- ❑ Parents concerned that their son/daughter will be dumped on the doorstep



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Other

- ❑ *Multi agency process is a barrier*
- ❑ CPP identifying the individuals funding
- ❑ CPP as an artificial CAP on the people who get comprehensive assessments
- ❑ Teams say people can't move because there is no one on the team with an understanding of the scope and variety of living/working etc., community capacity
- ❑ Regional Center staff is not at planning meetings
- ❑ Failure to have a professional with an understanding of the range of community living options attend the IPP's for DC residents
- ❑ We focus most on moving individuals with assertive families and not on individuals without this advocacy effort
- ❑ "not including me", "not listening", "not getting to know me"
- ❑ Regional Center deciding who to move and not asking the individual in the IPP meeting
- ❑ Waiting lists are wrong
- ❑ Too many people being moved, becomes hurried and short cuts are taken
- ❑ The rush to satisfy numbers required by RC executive management or DDS or the DC
- ❑ Reading referral packets without meeting the individual
- ❑ RRDP can be a barrier if they are not ready or obstructionist (Lanterman, Sonoma)



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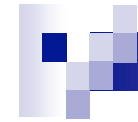
Planning with People Before They Leave - What Has Worked

Planning and Creating Energy to Support People to Move

- ❑ Visiting new community and ideally the new home
- ❑ Pre - placement visits
- ❑ Visiting with others who are already living in the community in Supported Living arrangements to get a better idea about supported living and what to expect
- ❑ Trial Runs - Individual overnight visit in new home gives agency staff a chance to re-think strategies and regroup
- ❑ Family agreeing to visit new home prior to visit and meeting new agency staff
- ❑ Making good connections with DC, RRDP staff by proposed service providers. Need to go out of your way to get their trust.
- ❑ Explaining the whole transition process in detail to the person identified to move.
- ❑ Allow the time and have a guideline for the move out process
- ❑ Allow the amount of transition time needed by the individual based on their needs and desires.

Details Around Planning

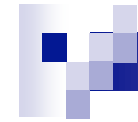
- ❑ Having a DMV ID card
- ❑ Having personal funds and a known income
- ❑ Having a Social Security card
- ❑ Success becomes greater when all parties are openly communicating and plan for all areas of placement (i.e., dentist, medical, psycho social, nutritional, medication)
- ❑ Regular, frequent meeting with all team members
- ❑ Identifying safety precautions



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Getting to Know the Person

- ❑ When developing a plan for someone to leave, it is critical to be able to spend time with direct support staff. Spending time with “the suits” can be helpful but generally is not.
- ❑ Focus on what my goal is “to be near my family” instead of planning on how to respond to catastrophic problems
- ❑ Identifying potential goals
- ❑ “Talk to me”
- ❑ Including me, not expecting me to be perfect, getting to know me
- ❑ Talking to my family
- ❑ Talking to the people at the DC who like me
- ❑ Addressing all areas of the person’s life/lifestyle, wants and needs
- ❑ ELP as a process for getting to know the person
- ❑ Using lots of ways to plan and check out information with the person (words, pictures, stickers, sampling options)
- ❑ Using alternative methods of communication (i.e., clip art, photos) to discuss and decide on living options, areas, etc.
- ❑ Spending face-to-face time with the person in an environment that is “safe” for discussion and exploration.
- ❑ Assessment work when the person(s) who do it have skill and experience, and are willing to commit the time and resources to that process. For example send a staff to stay on a unit with a referred person to “see” them in daily life.
- ❑ Service providers spend as much time as necessary to know the DC consumers by interviewing and observing the consumers prior to move - out.
- ❑ Developing a relationship. New agency core staff visiting regularly spending time with the individual and then staying in touch by sending cards and photos.
- ❑ Include all the advocates, from the person’s past, future and formal advocates.
- ❑ Family agreeing to visit new home, new agency and the staff and then understanding the difference between a group home and SLS
- ❑ Finding the person who know and cares
- ❑ Reviewing the Whole Person Assessment is helpful



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Funding Resources

- ❑ CPP, Community Placement funds, have helped with home costs and set up dollars
- ❑ RRDP's in some DC's are really helpful
- ❑ CPP funding allows true planning and resource development

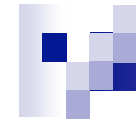
Planning with People Before They Leave - What Has Not Worked

Participants Have Alternative Agendas

- ❑ DC staff that know the person are not involved in community building for the person moving out
- ❑ Planning done by DC staff who don't know the community or support arrangements
- ❑ It takes too long for the plans to be developed
- ❑ Family does not want the person to move out
- ❑ Family states strongly "There is nothing that would meet my child's needs in the community"

People at Planning Meetings Don't Know the Person

- ❑ Lack of information and communication from the regional center
- ❑ Limited or wrong information about the person
- ❑ The "planners" don't know the staff and consumer
- ❑ Consumers don't know they have a right to choose, i.e., the right to choose life quality over cocoon like safety
- ❑ People who contribute information about the person "sugar coat" their behaviors or do not divulge information to expedite placement
- ❑ The individual does not know most of the people at their planning meeting



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The Planning Process is Inadequate

- ❑ Limited access to the person especially in terms of time away from the DC
- ❑ There is little opportunity for the potential new agency staff to spend time with the consumer with out DC staff present - "liability"
- ❑ We identify people for a "long range" goal of community living but current objectives are to get ready in "small steps"
- ❑ The SLS provider is "over confident", i.e., don't meet DC staff concerns with real plans
- ❑ Not everyone gets the level of planning as those in CPP
- ❑ Not planning completely
- ❑ Not including the individual
- ❑ Not developing a plan for when things go wrong before they go wrong
- ❑ Fragmentation in roles and responsibilities among DC staff leads to each person passing the buck and lack of follow through
- ❑ No "point person" or case responsible person who has ownership in moving the case along - the transition out process
- ❑ People involved in planning do not follow through
- ❑ The "ball" is often dropped
- ❑ Having different people do planning then the people who are developing or setting up services
- ❑ The individual was not allowed to go "off campus" and at the DC they are not themselves
- ❑ Individuals have not been to visit community living options for many years and assume they cannot live in the community - it "would not be safe"
- ❑ The planning process is often stymied by the so called lack of available community resources and insufficient attention to developing new options
- ❑ Failure to provide understandable information (including experiential) re: community living options
- ❑ "What is the function of spending 5 minutes only with a person referred to our agency"
- ❑ The DC client wants to live in an area that is not in his/her "home" R.C. area so planning is stalled due to resource development or political problems between regional centers



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- ❑ Individuals should get to visit the new community including day programs and other people who may be part of their new life - before they move

Fear, Confusion, and Assumptions

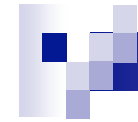
- ❑ Initial overnight possibly confusing and upsetting when the individual has to go back to the DC
- ❑ "I live with really scary people. How are people supposed to know who I am when they only see me in a scary place?"
- ❑ Family guilt that if the person could live in a home or community he/she would be living with their family
- ❑ What happens if it fails?
- ❑ If it fails and the person can't live with their family

Traditional Medical Model

- ❑ DC staff say people are not "ready" to move meaning they think behaviors need to improve, person needs to lose weight, medical conditions need to improve, etc.
- ❑ DC staff were the main source of information about the person, yet they were mostly unacquainted with the person to moves within the DC.
- ❑ Staff who did have a relationship with the person are not invited to meetings
- ❑ DC psychologist did not know the person he had written the behavior plan for.
- ❑ DC staff do not report issues or potential barriers in planning meetings. Information sometimes never comes out until person moves or it "slips" out through other processes

It's My Plan - Ask Me

- ❑ People are often not meaningfully involved in their own planning process
- ❑ "Include me in the process way in advance and make the process accessible to me by using "people first" language or by making accommodations for my disability"



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In Using Plans To Figure Out Where, How, And With Whom People Should Live - What Has Worked

Process, Importance of Good Planning

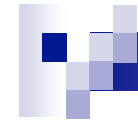
- ❑ Good team coordination with the Regional Projects
- ❑ Complete person centered planning process
- ❑ Having the DC put all pertinent information in writing re: health, welfare, likes, dislikes, etc.
- ❑ Pre placement assessment with key issues about environment and personal interactions
- ❑ Need to be able to take time. Can not rush the assessment of the process of the actual move
- ❑ Consumer should be the center of the process
- ❑ Getting information directly from the person
- ❑ Taking time to explain options to people
- ❑ Having good solid information on behavior issues to ensure that the person will succeed

Building Support Teams

- ❑ Providers who are flexible and creative
- ❑ Complete thorough planning
- ❑ Discussion and meetings with the person about their preferences
- ❑ Coordinating all resources and utilizing natural supports
- ❑ Collaboration among all involved - providers, regional center, advocate, RRDP, etc.

Identifying and Building Possible Relationships

- ❑ Interviewing potential housemates
- ❑ Developing a trusting relationship with the consumer - How do we get the time?
- ❑ Spending time with potential housemates - pre-placement visits together



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- ❑ Knowing who gets along with the person and is friends with them at the DC
- ❑ Transition from DC to I.C.F. which helped to determine proper support staff and possible room-house-mate

In Using Plans To Figure Out Where, How, And With Whom People Should Live - What Has Not Worked

Lack of Resources

- ❑ Finding providers with the type and level of expertise to support people with significant challenges
- ❑ Lack of necessary range of community resources and failure to develop necessary resources
- ❑ Regional Centers not sharing resources - refusing to consider individuals from other catchment areas

Lack of Planning

- ❑ Lack of information for consumers regarding community options
- ❑ "I changed my mind about how and with whom to live. It wasn't in the plan and it's not in the budget"
- ❑ "not listening to me, not including me"
- ❑ Making assumptions about the individual's likes and dislikes and thinking "They'll fit in" rather than thoroughly interviewing them to see what is best for them
- ❑ Using someone else's assessment
- ❑ Time frames on moves may limit options
- ❑ Plans are not developed and used early enough in the planning process and then they are not used.
- ❑ Having good solid information on behavior issues to ensure a plan to support the person will succeed

No Consumer Choice

- ❑ Giving too much deference to the desires of the parents
- ❑ When conservators insist on certain arrangements (i.e., location, staffing, roommates, etc.)



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- ❑ Not enough coordination between stakeholders
- ❑ “The DC and RC seem to feel they know what is best for my child and leave me out of decision making”

In Using Plans to Develop Budgets - What Has Worked

Completeness (Details)

- ❑ Knowing clear expectations of support and agreeing to that level
- ❑ Having all of the information regarding medical, psychological, and behavioral issues
- ❑ Plan and budget for the unexpected
- ❑ Know the impact of transition on benefits (Social Security, VA, etc.)
- ❑ Knowing the true support needs of the consumer to determine hours needed

Individual, Flexibility, Independence

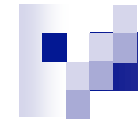
- ❑ Providing and promoting creativity and individuality
- ❑ Self Determination and Support
- ❑ CPP flexibility

Teamwork Gives Adequate Input To The Plan

- ❑ Creativity and Teamwork
- ❑ Team effort to help cover all aspects of budget

In Using Plans to Develop Budgets - What Has Not Worked

CPP Implementation



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- ❑ How long do CPP agreements (funding rent and property damage) continue?
- ❑ Transfer of funds from CPP to agency for the individual is confusing and very time consuming

Cost Cap

- ❑ Conservator/Payee not easily accessible
- ❑ Difficult to know what all actual costs would be for the individual
- ❑ I honestly wish to support this plan but \$346,000 a year
- ❑ People being served in the community are costing more that they did in the DC

Benefits Transition

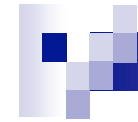
- ❑ Four people who have moved from the DC had incorrect social security numbers for SSA/SSI benefits
- ❑ Time lag in SSI transition from DC can leave money short and should be put in budget

More Flexibility

- ❑ Beyond the initial budget some component of allowing for additional funds for repairs/renovations need to be available for some consumers
- ❑ Complete start up budgets
- ❑ Unforeseen expenses - budget does not cover unexpected expenses of additional hours
- ❑ Low flexibility with plans

What come first? Money or the Person?

- ❑ Budgets are “capped” due to resource limitations rather than what people need
- ❑ Some RC’s have a pre-determined budget which is limited and non-negotiable and not person centered
- ❑ Failing to identify the specific needs/wants of an individual



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Access to Resources

- ❑ Regional Center disagrees on the support that is needed
- ❑ Failure to identify all available resources to take full advantage of federal funding stream
- ❑ Poverty of individual limits housing possibilities that may make the difference between success and failure of community living
- ❑ Getting generic resources in a timely manner

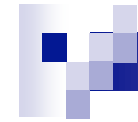
In Helping People in Their Transition - What Worked

Listening, listening, listening

- ❑ A home that reflects the consumer's preferences, behaviors, fears, and proven strategies
- ❑ Asking the person what she prefers in terms of a home setting, job opportunities and support staff qualifications
- ❑ Respect the individual to know what they want and need
- ❑ "Being heard"

Interagency Partnerships

- ❑ Including day/employment program staff in transition meetings and planning
- ❑ Allowing for day visit/trial to program during transition
- ❑ Transition meeting with DC, SLS agency and support team including direct service staff
- ❑ Need all paperwork from DC including birth certificates, social security, Medi-Cal, etc.,
- ❑ All parties working together
- ❑ Good Planning
- ❑ Reworking the plan
- ❑ Having a fully staffed RRDP office to assist with transition needs in a timely fashion
- ❑ Having the completed ELP on hand



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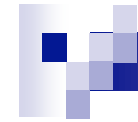
- ❑ “We made sure we had all the players involved: RC, case manager and fiscal, RRDP, DC staff, individual, friends, family, housing authority, group home, community college”
- ❑ Lining up Medical, dental, mental health providers in advance of move out
- ❑ Frequent communication between DC and community staff so there is a more comprehensive or continuous transition - a fade out (of the DC) to a fade in (to the community)
- ❑ Getting the community doctors and medical staff to confer and consult with the Dc unit physicians, psychologist, etc.
- ❑ Plans support providers being flexible and open to learning and changes
- ❑ Thorough and good plans
- ❑ Supportive regional center
- ❑ Good partnership with RC Service coordinator
- ❑ Identifying a key person @ the DC who can be contacted with questions and to be a key person to visit during transition

Commitment

- ❑ Consistency for the person and their staff assistance and family and friends
- ❑ Staffing the home with people the consumers are familiar with and know and trust
- ❑ Staff that can stick it out through the hard days to get to the good day
- ❑ It is important to know that when someone first moves out there may be rough times ahead and we need to make a commitment to that person to keep supporting them through the rough times

Visits to the New Community

- ❑ Being able to have the consumer visit at least 2-3 times in the community in which they will live
- ❑ Lots of visits and getting to know the person well



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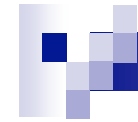
In Helping People in Their Transition - What Has Not Worked

Transition Timelines That Are Too Short

- ❑ Not having access to meeting with the consumer and the people who know them
- ❑ Bureaucracy limits access to consumer
- ❑ Trying to do too much too soon. Day program every day from beginning, too hard, too many new people, things, activities
- ❑ Many regional centers offer no compensation for the work done during the transition period. There is a lot of time and effort done prior to the move.
- ❑ Scheduling through a very limited RRDP. Visits taking 2-3 weeks to set up
- ❑ Not taking or making the time (on the part of support staff/agencies) to recognize and assist with fears that accompany such changes in one's living situation
- ❑ Not recognizing that there can be a period of anxiety due to change and then giving the person time to adjust
- ❑ Having to rush the transition process because of CPP fiscal year deadlines
- ❑ Having time with the consumer before the move without the DC staff
- ❑ Rushing timelines to satisfy bureaucratic decisions and not the individual

Interagency Lack of Communication

- ❑ DC staff "This person can not be served in the community. His medical issues are too severe."
- ❑ Medical and clinical evaluations not up to date, or missing when packets arrive from DC. It is difficult to do follow-ups
- ❑ Not having the complete history of the person you will be serving
- ❑ Too many people in the mix - power, control, turf, issues
- ❑ Regional Center not as responsive as needed
- ❑ Better relationships with DC staff
- ❑ Lack of organization and communication with DC
- ❑ Difficulty obtaining necessary information, i.e., birth certificates, proof of income, etc.



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- ❑ Poor communication within DC. When we arrive to pick up consumer for appt. they are almost always not ready, sometimes the line staff doesn't know they were planning to leave

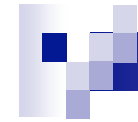
Fears, Lack of Knowledge

- ❑ Day program did not have same commitment as SLS agency did in supporting a person who presented some challenges
- ❑ Staff that are not prepared to deal with unpredictable behaviors
- ❑ "I need to know that when I move into my home that the agency and staff that support me understand things may be rough in the beginning (very rough) for a short period or a long one, and I need the commitment that they will stick it out with me"
- ❑ "I am nonverbal and my staff does not observe me enough to see if my lifestyle is working for me"
- ❑ Mentally preparing hem/her for the change and making sure there is plenty of support
- ❑ Don't let them feel abandoned
- ❑ "After all of the time living in the DC I was put in a position to explain my dreams, preferences, dislikes to someone I only met twice. How do I know I can trust?"
- ❑ Assuming we know what people want
- ❑ How long it takes - person is losing hope and sanity while waiting
- ❑ "I was told if I don't behave I can't move out and I will be forced to move back if I have problems"
- ❑ Follow through on day program planning

In the First Month After People Move - What Worked

Partnership and Commitment

- ❑ Forgiveness for inevitable adjustments some might "blame" or label as "mistakes"
- ❑ Expecting rough spots (that have been identified - hopefully) and plan for them
- ❑ Self-determination



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- ❑ Flexibility - responsiveness
- ❑ Freedom to do what makes sense

Know and Respect the Consumer

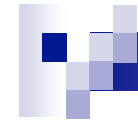
- ❑ Freedom to choose own food, staff, house, etc.
- ❑ Don't make too many changes in their life
- ❑ Being respectful of who they are and the years they spent in the environment they left
- ❑ Try and meet them where they are at and not where you want them to be
- ❑ Get to know them

Staff Development

- ❑ Arrangements for DC staff to assist training our Supported Living staff
- ❑ DC staff attending PATH for the person
- ❑ Closely monitored trainings for SL staff "everyone on the same page"
- ❑ Immediately seeing the moved individual and seeing increased happiness, better mood, etc.

Communication

- ❑ First appointments with medical and mental health provider within first month
- ❑ Need 30 day follow up meeting with DC and SLS agency
- ❑ Allowing for SLS staff transportation to day/employment program while other arrangements are dialed in
- ❑ Consistency
- ❑ Being available to the person regularly to help problem solve, monitor and enjoy their new life
- ❑ Open communications with consumer's family and support staff
- ❑ Frequent visits to community homes and present yourself as an advocate that is able and willing to assist with challenges that may arise
- ❑ Identifying a key staff person who can be available to answer questions and visit during the first month



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In the First Month After People Move - What Has Not Worked

Financial

- ❑ Getting the SSI/SSA Medical in a timely manner and switched over
- ❑ Money does not follow the person!! Social security and Medi-Cal in limbo for 6-8 months.
- ❑ SLS agency had to front all personal \$ and paid for Dtrs. visits and prescriptions for two people
- ❑ SSI medi-cal transfer to new area
- ❑ SSI/SSA Medi-Cal - Being cancelled, not started, denied, etc.
- ❑ Not having DMV ID card, medi-cal card, or access to birth certificate
- ❑ The individual does not have the financial means to move out.
- ❑ Helping support staff to become aware of how to budget so they can teach the concept
- ❑ Housing (landlord/tenant - discrimination) issues
- ❑ Consumer does not have enough money for living expenses (SSDI status in transition)

Medical Insurance Issues

- ❑ Necessary medical and psychiatric supports were not available once he returned to his community
- ❑ Not being able to establish new dentist/psychologist/doctors until consumer actually leaves

Day supports

- ❑ Day program not wanting to accept a person back into their program, who "failed" because of behaviors in the past
- ❑ Receiving day service/work service that promotes meaningful work/activities

Staff Development



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- ❑ Training providers staff (i.e., smearing, seizure management) while new client has already been placed into community home
- ❑ Staff not being properly trained, not reading history of consumer
- ❑ Finding the right staff
- ❑ SLS staff couldn't communicate with the consumer who uses fluent sign language

Individual Structure

- ❑ Why can't I see my friends at the DC? I want them to visit me in my new place
- ❑ Giving too much freedom with too many choices
- ❑ Not realizing the person may have come from a very regimented lifestyle

In The 2nd Thru 6th Month After People Moved, What Worked

Support Staff

- ❑ Continuous staff meetings and training
- ❑ An understanding of hiring and terminating staff
- ❑ "My staff helps me find ways to keep busy and have fun doing things I want to do"

Choice

- ❑ Self-determination
- ❑ Listening to messages from individuals about what they want
- ❑ Seeing a person change and grow because of: access to things they love, exposure to lots of new opportunities and activities, people who care and believe in the person around with the person each day, using a planning tool (PATH, MAP, ELP), listening



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- ❑ “My daughter is speaking in clearer phrases, wanting to help out around her house”

Clinical support: having a strong professional team (i.e., psychologist, psychiatrist, behavioral specialist, dietician, psychopharmacologist, etc.)

Flexibility and problem solving

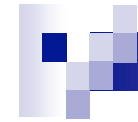
- ❑ Being flexible with goals/plans
- ❑ Continue being available often to work on issues before they become problems and support everyone involved

Trust and commitment

- ❑ Continuity in routine
- ❑ Establish trust
- ❑ Live up to commitments made to individuals and their teams

Follow up visits

- ❑ Continuing visits frequently with planner and regional center
- ❑ Visiting the consumer in his new place and seeing him do well
- ❑ 30 day quarterly meeting
- ❑ Getting the “team” (consumer, family, RC, SC) and provider together to create the ISP



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In The 2nd Thru 6th Month After People Move, What Did Not Work?

Family understanding

- ❑ "I expected greater staff stability for my son, but his favorite staff has already been "reassigned", and how his home is more chaotic, not less"
- ❑ Professional don't include training and re-bonding for the family to get to know their child again
- ❑ Many have been placed because of behavior problems that left the family unable to cope
- ❑ Families need support

Planning glitches

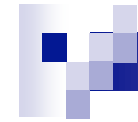
- ❑ Improper debriefing of consumer's background or history to the staff supporting the consumers
- ❑ Not understanding the consumer's prior history with certain personality styles that can trigger challenges -
- ❑ Initial hire looks solid - problems don't arise until 2 months of staff and consumers working together Failure to understand the person's abilities and preferences
- ❑ Individuals not following person centered plan
- ❑ Failing to observe specific areas of need initially overlooked

Lack of time to adapt to the change

- ❑ The consumer has a problem with choices coming from a restrictive environment
- ❑ Forceful or aggressive resolution oppose to patience and nurturing approaches
- ❑ "Be patient. This is a really huge change for me before you decide my plan is a failure"

Resource Gaps

- ❑ Resources promised aren't delivered and results in problems/failures
- ❑ Why is SLS program support needed? Why is there not a day program?



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In Thinking About People Who Were Identified To Move And Haven't, What Worked

- ❑ There is hope
- ❑ "Please start planning so I can move"
- ❑ There are some individuals who have waited a long time and have a certain level of maturity
- ❑ "People have been kept safe a little longer"

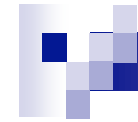
In Thinking About People Who Were Identified To Move And Haven't, What Has Not Worked

Lack of Community Capacity

- ❑ Transition time is too lengthy and causes great anxiety for consumer that can be antecedent for negative behavior
- ❑ Insufficient community capacity to fulfill the promises of the person centered plans
- ❑ Timelines being pushed back because there's not enough qualified staff to successfully support people in the community
- ❑ Need more, stronger, supports
- ❑ "I was assessed by an SLS agency and ready to start moving. The RC stalled on funding, the SLS agency had to take someone else to work with and I ended up in a B&C just to get out of the DC"

Lack of Support for SLS as a Viable Option

- ❑ Even when IPP recommends community movement, individuals are slated for movement to a category of already existing services
- ❑ Person identified to move considered only for facility or group home placement because of, perhaps, misconceptions about SLS as an option



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- ❑ Determinations made based on the current availability of resources rather than considering possible resource development

Family Concerns

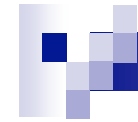
- ❑ Family is not sure of the role of the regional center. They have been a part of the DC for so long
- ❑ Too Scary
- ❑ Family opposition to the referred move, resulting in the identified consumer following in suit
- ❑ "My child won't be as safe in the community"

DC Uncertainty About Adequate Support in the Community

- ❑ Not being notified by the DC that this person is actually on referral to the community
- ❑ Expressed resistance from the DC staff
- ❑ "I will make sure that _____ gets everything he/she needs before moving - which in some cases is a way of preventing the move
- ❑ Working together with the DC staff on what is needed for a person so they can successfully be placed in the community. There are divergent views that stand in the way
- ❑ "Providers in the community don't do as good of a job as we do in the DC"
- ❑ I will resist any attempt to move "my" folks

Frustration

- ❑ "I'm stuck" "Help me figure out how to move"
- ❑ The longer it takes the more the person is not trusting us
- ❑ Once a delay or "hold" is placed on having a client move there is unclear role of the agency in continuing to keep in touch or not. Person experience with one client is that we were told the client was on "hold" to stabilize several issues but we've had no contact with the client of DC staff or transition team for months
- ❑ Very frustrated individuals



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Legal Issues

- ❑ DDS refuses to keep good statistics on who is identified to move so they cannot be accountable for any but those on CPP
- ❑ Court issues are not worked out
- ❑ Court ordered placement without enough planning

In Thinking About People Who Moved And Returned To The Dc Within 3 Months. What Worked

- ❑ Knowledge of consumer's abilities, weaknesses, medical, psycho/social status, over all health concerns that have become issues and/or reasons for the return to DC
- ❑ We have begun to try to support this person differently, now we need to be careful not to give up

In Thinking About People Who Moved And Returned Within 3 Months, What Did Not Work

Poor Planning

- ❑ The planning process team broke down
- ❑ No contingency plan
- ❑ Not having needed supports
- ❑ Ill prepared staff and providers



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In Thinking About People Who Moved And Returned to The DC After 3 Months, What Worked

- ❑ Nothing!
- ❑ Learning about what worked and what did not making a more successful next choice

In Thinking About People Who Moved And Returned After 3 Months, What Did Not Work

Insufficient Supports

- ❑ Original plan did not pay enough attention to mental health needs - moving to an area with no mental health supports
- ❑ Placed with insufficient supports
- ❑ "I am a dad of a person who moved to a group home from the DC. No reliable arrangements were made for transportation to appt., or work. I keep getting calls to transport. No one seemed to know how to set up reliable transportation. I returned my son to stay at the DC
- ❑ We simply were too busy. We agreed to support this person when we really didn't have the capacity
- ❑ Staff ration gave the person less attention than they needed
- ❑ Lack of trained support staff to assist an individual with mental health issues
- ❑ The level of supports in the community is not as high as in the DC
- ❑ Consumer choice- mismatched with care provider
- ❑ Over-regulated resources unable to adapt to the individual needs due to licensing issues
- ❑ DC staff did not see SLS as a viable option. They only considered a group home placement that did not work out successfully for the person
- ❑ Assuming that what people wanted was static, not changing the plan as the person changed desires, support needs, etc.



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Think About People Who Have Been Referred For Admission To A DC - What Has Worked To Keep Them Out (In The Community)

Professional Teaming, Sharing, and Collaboration

- ❑ Regional Center free up money to provide services needed to stay in community
- ❑ Supportive and clever case manager
- ❑ Collaboration between supporters and regional center
- ❑ RRDP's deflection process - if it works as statute says and if RC and RRDP collaborate
- ❑ Sharing ideas and resources with other people/places
- ❑ Planning as a team

Community Services Designed for the Person

- ❑ One parent was thankful that she could have her daughter temporarily admitted for care after surgery and then she was able to be released back to the community.
- ❑ Positive was having DC staff able to provide appropriate medical care/physical therapy until her daughter was stable and ready to return to the community
- ❑ Children's crises homes
- ❑ Identifying as early as possible that this individual needs extra attention, support and choices. Not waiting until the last moment when a crises has already developed

Building, maintaining, bridging, nurturing family and friends

- ❑ Strong planning team participation
- ❑ An involved and supportive circle of friends, advocates and providers
- ❑ A strong circle of support: Parents, program staff, medical and regional center
- ❑ The belief that a creative approach can work and the all of the team has to work together
- ❑ Family and friends who are proactive



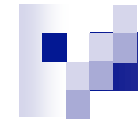
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- ❑ Strong family support created by the motivation one needs to learn quickly and fully the in's and out's, pros and cons of DC
- ❑ "I visit people who've moved and give them moral support and continued friendship"

Think About People Who Have Been Referred For Admission To The DC What Has Not Worked And They Have Been Admitted

Lack of needed services

- ❑ People not listening to the consumer's wishes
- ❑ Going from vendor to Vendor - build severe reputations
- ❑ Lost History's
- ❑ Willingness to hear that more supports are needed before final crises occurs
- ❑ The need for greater teamwork between supporters, supporting agencies and regional center staff to response to the individual now and not at our convenience
- ❑ Poor communication of person's needs to people who could help and with enough time to make changes
- ❑ No successful psychiatric intervention
- ❑ No adequate medical and generic supports
- ❑ RC's do not do adequate resource development while a child is in crises home so at then of 60-90 days kid goes into DC
- ❑ Insufficient space in children's crises homes
- ❑ There is not equivalent to the kid's crises homes for adults
- ❑ Lack of emergency supplemental services which if provided by the regional center could have prevented return to DC



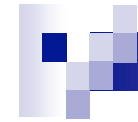
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Finances/Funding

- ❑ Not all people are referred for deflection assessments
- ❑ RRDP's are not helpful
- ❑ RRDP assessment was biased because the person who left and lived in the community did not have a "good" day on day of RRDP visit. The person was identified as someone who would benefit from returning to DC
- ❑ RC's do not attend all DC IPP's even when the RC is the conservator
- ❑ RC's do not follow-up on the deflection recommendations that we provide
- ❑ Budgets crunch the amount of support staff and attention needed to transition the consumer appropriately

Other comments:

- ❑ Convenience to regional center: It is the easiest option (DC) when the family is not present
- ❑ Regional Center Service Coordinator thought the DC was a reasonable option without exploring additional options
- ❑ Court ordered admission even though we had a community placement identified
- ❑ Poor collaboration b/w regional center and RRDP
- ❑ DC staff who knew the person who moved from the DC, advocated that the person should return to the DC because they were "not ready"
- ❑ CPP quotas are low
- ❑ DC's are self-perpetuating and institutional staff have a strong interest in self preservation



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In General - What Worked

Consumer choice

- ❑ Opportunity, choices, productivity
- ❑ Self-determination
- ❑ Encouraging self reliance, independence
- ❑ Regular opportunities to gather circle members (people close to the person receiving services) to assist with problem solving in a context where the focus person is respected - shares some power
- ❑ Recreational - Introducing as many new hobbies and then letting the consumer decide what he/she enjoys to do. It's his/her choice!
- ❑ Providing the consumer with the opportunity to experience common and/or fundamental situation and interactions they may have gone a lifetime without
- ❑ Freedom of living in his own apartment
- ❑ Education of consumer regarding choice/preferences
- ❑ Continuous support with adjusting - especially choices

Teamwork, circle of support, staff, family, community

- ❑ Working as a "team"
- ❑ Follow-ups and correspondence to all support teams
- ❑ Believing that the individual knows what works for them and what does not
- ❑ All stake holders working toward common goals
- ❑ Having regular circle meetings with the individual to share celebrations and problem solve. Simple reminder that this is the person's new home and place
- ❑ Conducting PATH's with a consumer. This has allowed dreams to come true and obstacles are over come.



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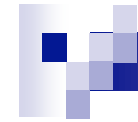
Staffing Based on Consumer Match

- ❑ “Having staff that stick with me while I get used to my new life even when I do things they might not like”
- ❑ Having a good connection (relationship) Between the individual and staff
- ❑ Finding support staff who truly understand the values/philosophy of supported living
- ❑ Trust between SLS provider, DC staff, and Regional Center staff, that we know what we are doing
- ❑ Planning, communication, teamwork, know me, not giving up

In General - What did not work

Systems Issues

- ❑ Need more information about SLS as an option many people do not know about it, regional centers do not disclose the information
- ❑ Transition from one RC to a new RC. They seem to fight with each other leaving the consumer and SLS agency in the middle.
- ❑ Agreements and plans need to be changed once person has been in the community over a year. They are no longer followed by the DC liaison but by “regular” RC service coordinator
- ❑ “Information in my RC file that may be old or inaccurate. The negative information limits my option because some providers do not think they can help me because of it.”
- ❑ No planning, communication, no listening
- ❑ Regional Center staff who seem not to know what the right hand is doing
- ❑ Court Orders - Forcing placement of dangerous people with very severe reputations
- ❑ Need more providers
- ❑ Consumer concerns - “This is taking forever”
- ❑ “I was in placement for ten years and lost contact with my family, how do I get information about them?”
- ❑ Lack of reliable emergency support (i.e., mental health, medical, inpatient, extra staffing)



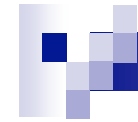
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Abuse of power

- ❑ Support staff who misunderstand the relationship and take advantage of the “position of power”
- ❑ “Why do people who don’t really know my son have so much power to control his and our lives?”
- ❑ Control
- ❑ Parents have a wrong idea of who is in control
- ❑ The need to determine whether or not the individual is “ready”
- ❑ Treating consumer as a “pet” instead of with respect and as a human being with real emotions, ideas, concerns, etc.

Fear and Failure

- ❑ Failure to implement writs (court orders) in a timely manner
- ❑ Failure to monitor the person’s financial situation causing to lose Medi-Cal benefits
- ❑ Failure to provide equipment to secure safety, not only for the person but the support staff as well
- ❑ “We have had a problem receiving funds for consumers from the Regional Center in a timely fashion that is conducive to supporting the consumer”
- ❑ Due to overload of caseloads, Service Coordinators are failing to fulfill their immediate responsibilities to the consumers, thereby the agency is stuck filling the gap
- ❑ Peoples fear about past problems plays too large a roll in the present
- ❑ Any little thing sets off big fears
- ❑ Expectation of failure leads to nitpicking of every little issue and stalling of timelines



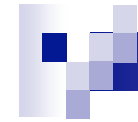
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What Is Working That Could Be Strengthened

From The Work Done In The First Part Of The Day - Organized Into Themes By The Participants

Partnerships/Collaboration

- ❑ Hold regular, frequent meetings with all people to bridge communication and create understanding
- ❑ Make every possible effort to better the relationships with DC staff, family members, and all people involved in the consumer's life
- ❑ Increase communication within agencies and between agencies
- ❑ Partnerships among players must be strengthened
- ❑ Collaboration between existing community resources that are serving people moving of DC's and sharing of successes and pitfalls - less time spent re-inventing the wheel
- ❑ Increase collaboration among stakeholders
- ❑ Strengthen working relationships between RC and SLS agency to reduce the "blame" mentality while still holding each other accountable
- ❑ Sharing knowledge and strategies regarding things that have worked
- ❑ Need follow through between agencies
- ❑ Communication between agencies
- ❑ Providers, RC staff, RRDP staff, and families attending follow up meetings during transition and at 30 days
- ❑ Strengthen concept of Partnership - especially with consumer
- ❑ Create a learning culture and a culture of partnership, trust, and respect within the support team and the individual after the move
- ❑ Develop better relationships with DC staff so there is no fear and intimidation on either side.
- ❑ We can improve inter stakeholder communication and collaboration
- ❑ Improve interagency communication so that each agency knows what the others require to smooth out the process and make timelines less traumatic for people moving out
- ❑ Sharing of information about resources between various stakeholders
- ❑ Building a better relationship between regional center and SLS agencies



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Increased Number Of Vendors

- ❑ Have more supported living services available
- ❑ At the DC many people care a great deal. They may make good vendors
- ❑ Develop needed services on an individual basis
- ❑ Increase the number of high quality community living options
- ❑ Providers continue to accept folks just out of the DC
- ❑ More vendors are needed by regional centers

Housing

- ❑ We need changes in the Section 8 Program
- ❑ Consumers need an income that will allow choice about where and how they want to live
- ❑ Increase affordable housing
- ❑ Need lower rental prices for homes

Community Resources

- ❑ Eliminate the culture of poverty among folks leaving DC used to getting all of their needs met without having to go without
- ❑ Close the institutions and put the \$ into community services
- ❑ Funding from the government
- ❑ Continue to find ways to increase "community capacity"
- ❑ Build partnerships with the medical community
- ❑ Increase housing options
- ❑ Develop emergency response services
- ❑ Utilization of community resources (i.e., transportation)
- ❑ Doing just a one time payee change until the paperwork catches up (SSI, Medical) this can be done for three months



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- ❑ Relationship between consumer and the community they choose to live and be active in
- ❑ Continue to find ways to strengthen/build relationships between people receiving services and community: communication, education, access,
- ❑ Strong advocates in the community
- ❑ Developing more community resources i.e., jobs, day programs, SLS providers etc. To provide options for a greater number of people.
- ❑ Welcoming communities

Consumer Direction

- ❑ Consumers should be included at the policy making/setting level consistently
- ❑ Including people with developmental disabilities in the planning process thereby improving the transition plans because they will be more flexible, creative and responsible to the changing needs of the individual
- ❑ Visits to consumers at the DC can be arranged as many times as needed prior to the move. The service providers can know the consumer from direct communication and observation instead of review of the referral packet
- ❑ Assist the consumer to visit his or her friends at the DC if desired by the consumer after the consumer moves out into the community
- ❑ Make sure the individual is working towards what he/she wanted to do with their life
- ❑ Try listening to what people want and not what we want for them We can be more inclusive and responsive to the consumer voice and the voices of those that care about them when appropriate
- ❑ Working more and more toward supporting people rather than containing people
- ❑ More training for community services to understand d that people with disabilities are community members
- ❑ Training opportunities for consumers, family, service providers and regional centers on how to obtain/promote “natural supports”
- ❑ Educating the consumer and family about the whole culture shock
- ❑ Hearing the consumers voice and respecting it: Where they live, who they live with. How they want to live.
- ❑ Ability to spend the time needed to know what the consumer wants
- ❑ Structured choice within safe limits



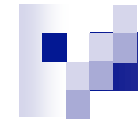
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Staff Development

- ❑ Increase staff training by including direct service staff during the discharge process
- ❑ Reward direct service staff in ways that promote longevity and commitment
- ❑ Increase staff development by having biweekly meetings
- ❑ More in depth hiring process so we can match consumers with those who support them
- ❑ Continue to value and listen to direct service staff while providing training about respect, value, judgments, etc.
- ❑ More paid training for SLS staff
- ❑ We can give good clear information to people - all stakeholders- about what SLS and other community options are
- ❑ Some Regional Projects are more effective than others. Could they coordinate among themselves to share what works to make them all more helpful to the DC's they serve?

Finances/Funding

- ❑ More funds needed for SLS staffing
- ❑ Money should follow the person when they leave the DC
- ❑ More money for employees and trainings
- ❑ Close all the DC's and reserve all the savings and the price of land to DD community systems to improve wages etc.
- ❑ Find a way to reimburse the service providers for making visits to consumers at the DC prior to provision of services
- ❑ The option to have a potential provider start service while consumer is still in DC so transition will be accompanied with a familiar face
- ❑ All consumers should receive \$2000 cash with they move out for personal expenses



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Health Care

- ❑ Universal health care!
- ❑ More medical services options for those on Medi-Cal
- ❑ Make all consumers exiting DC's provisionally eligible for SSI/SSDI, Medi-Cal, and IHSS so that there are No gaps in personal funds or eligibility for those services
- ❑ Higher Medi-Cal rates of payment
- ❑ IHSS stays

Crises Intervention

- ❑ Need more crises intervention support so consumer can stay in their home or community when complicated problems arise
- ❑ Improve ability to respond proactively rather than waiting for a crises

Systems Change

- ❑ Prior to moving disseminate the relevant information about the person in order for the support staff to effectively support the person
- ❑ Better planning for the first six months
- ❑ Good Assessments work
- ❑ Not enough people know how to do an assessment well
- ❑ Need more training on how to do assessments well
- ❑ Assessment is happening but needs to be strengthened: Meaningful involvement of people who know and care about the individual
- ❑ Educating individual as to their choices
- ❑ Assessment over time - really get to know the individual
- ❑ Involvement of necessary clinical staff to plan for health care needs
- ❑ Taking it to the streets - ALS the protests and demonstrations of Nov. and Dec. '03



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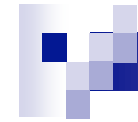
- ❑ Self-determination should be available to everyone who wants it. Rights to privacy and autonomy
- ❑ Quality assurance based on assessment of outcomes for consumers
- ❑ Easier planning and availability through the DC's for transition
- ❑ Financial follow through: 1. Paperwork filled out promptly. 2. CPP money given to consumer 3. Medi-Cal and Medicare not delayed. 4. SSI and SSA and Money flow smoothly. 5. Transfer to RC from DC faster
- ❑ Supporting with money as well as worked, people First and Self-Advocacy Chapters
- ❑ Sufficiently sound support needs of consumers exiting DC's
- ❑ Strengthen teams at all regional centers to find alternatives to DC.
- ❑ Reward RC's that not only get folks out but also don't put folks in
- ❑ Continue providing information and education to stakeholders about what SLS is and what it is not. This will help us move away from the readiness excuse and enforce the value of community integration
- ❑ How do we better inform people who use services

Consumer Education

- ❑ Setting up more recreational outings to help consumers to widen their knowledge of life
- ❑ More education for families and individuals about SLS and options
- ❑ Improve leadership and collaboration to focus on people being in LRE and SLS based on their needs not based on parental fears or DC staff fears about job security
- ❑ People understanding options and being supported to express views
- ❑ Listening to people who are non-verbal
- ❑ Education so that everyone has the same understanding of what services are available

Other Comments

- ❑ More agencies willing to support people than could possibly be "maxed out/full" so people truly have choices in supports, geography, etc.
- ❑ Other peoples thoughts and feelings regarding the disabled community
- ❑ Professionals who cannot put their own self interests aside and truly believe in the individual that they work for



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- ❑ Turning the rain into sunshine
- ❑ Transition time should be for transition
- ❑ Removal of the between agencies and the client wanting to move
- ❑ Implement self determination and abolish regional centers
- ❑ Regional center service coordinators should attend SLS values and philosophy training on an annual basis
- ❑ People who have lived in the community all their lives can't get what a CPP person can today
- ❑ All agencies, families, etc., working toward the same goal of the person getting a life

What Is Not Working That Could Be Changed

From The Work Done In The First Part Of The Day - Organized Into Themes By The Participants

Staff Support and Training

- ❑ Offering educational classes and workshops to SLS providers and consumers
- ❑ DC, RCRC, and RRDP staff should be assessed and then rewarded or dismissed based on performance in consumer satisfaction with outcomes and support
- ❑ Better matches in staffing
- ❑ Decrease caseload of service coordinators
- ❑ Educate the DC staff about community supports and services
- ❑ Educate natural resources about our consumers
- ❑ Educated support staff to increase skills
- ❑ Offer competitive salaries for direct service staff
- ❑ Training is to abstract needs to be concrete
- ❑ Training for direct service staff to insure safety (i.e., suicide, Alzheimer's, etc)
- ❑ There is too much responsibility for too few people
- ❑ Address the concerns and fears with agencies about community and client health and safety
- ❑ Agency unaware of what the liability and boundaries are with high risk clients



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- ❑ Day program providers are scared of the written referral without meeting the person, so they decline the referral

Change in Philosophy

- ❑ Clear promises made for time lines build on client needs
- ❑ More comprehensive plans before the move
- ❑ CPP has numeric goals to DDS - Doesn't focus on individuals
- ❑ Keep provides small - Right now we don't reward good support, especially new providers
- ❑ Better support with community integration
- ❑ Consistent implementation of SLS regs. by all regional centers as well as vendors across Calif. This is about consumer choice not RC or vendor choice
- ❑ Strategies to overcome the DD communities isolation from the general community and get community buy in to inclusion
- ❑ Give up the Readiness Models
- ❑ Train, educate, contract out for facilitators for planning for every DC resident who understand community capacity and do not believe medical model or readiness model are bars to community placement
- ❑ Streamline the regulations/rules in a way that agencies can work collaboratively and not compete for the same money
- ❑ Get buy in and support from high profile influential people (politicians)
- ❑ System of referral and actualization to services must be more easily understood, accessed and coordinated
- ❑ Over bearing family, who are in control, that do not treat their family members with respect and treat them like they are incapable of making informed decisions
- ❑ Community acceptance: housing, medical, work, relationships, neighbors

Partnerships/Collaboration

- ❑ Better communication between RC and SLS
- ❑ Need clear roles, relationships, and expectations of all "team" members prior to and after move

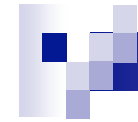


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- ❑ Communication, deeply listening, to concerns expressed by all players
- ❑ Organized, planned “gatherings” between RC staff and RRDP staff
- ❑ Increased knowledge of DC staff of community resources
- ❑ Need to have ALL information about the person. DC staff share what they know and make available the archived information
- ❑ Trust between stakeholders
- ❑ Just what this gathering was intended to do: “Collaborative Dialogue”; vendors, RC, DC, DDS, RRDP, families, consumers, etc.
- ❑ Ability to discuss concerns and fears openly to help in the process of overcoming them.
- ❑ Build better partnerships with Dept. of Mental health and Emergency Response teams
- ❑ Regional Centers mandated to attend all the IPP’s for the consumers. Currently many IPP’s at the DC do not include the regional center
- ❑ Fully include everyone necessary to the planning process: informed consumers, staff who care, professionals with knowledge of the range of community options
- ❑ Greater collaboration between Service Coordinators and “specialists” do that SC’s do not continue to carry the responsibility of identifying and securing critical supports, sometimes resulting in DC placements, when a situation becomes too critical
- ❑ Good communication between all involved
- ❑ Greater support and collaboration with supporting services to identify what needs to be strengthened and responding to those needs, once identified, more timely rather than accepting for what is and getting lost in a sense of inertia
- ❑ Open dialog along the path of partnership without judgmental actions
- ❑ Multi-agency dispute resolution for the benefit of the individual served

Regional Center Responsibility

- ❑ Better communication within the regional center
- ❑ Have DC’s enforce the least restrictive alternative mandate by ensuring all regional centers do their fair share of CPP goals and the development of SLS



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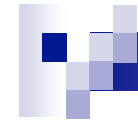
- ❑ The coordination of the requirements and guidelines of the agencies involved in helping the consumer get out of the institution and into the community
- ❑ Waiting lists for placements have caused lost opportunities for other DC residents

Self -Advocacy and Self Determination

- ❑ Listening to people with developmental disabilities and advocating with them on their issues
- ❑ Consumer should get full picture of who will do what by when if consumer wants to move to the community
- ❑ Implement Self Determination fully and completely as a right of citizenship
- ❑ No more power struggles about who is right. Consumer is the main focus
- ❑ Listen to what the consumer/family wants instead of pre decision made by RC/DC in terms of living arrangement
- ❑ Too many professionals making life decisions for people that they barely know
- ❑ Process should be more consumer driven not timeline driven
- ❑ Assistance for people to find their voice
- ❑ Giving consumers more advocacy over their own lives

Funding

- ❑ Take better advantage of available funding sources (e.g., federal Medicaid waiver funding)
- ❑ Fund resources to ensure a secure and successful placement
- ❑ Close DC's and focus resources and energy on community living Efficiency of Regional Centers to provide funding in a timely manner that is conducive to adequately supporting consumers
- ❑ Increase in pay for personal attendants/ direct service staff
- ❑ Individual's SSI, SSA, Medical, money must follow them or flow to them seamlessly into the community
- ❑ Close the DC's and spend the money on quality options in the community
- ❑ Service providers in the community should be paid more that DC staff (or at least equal)
- ❑ Funds must be available to subsidize rents when necessary
- ❑ Rates and funding based on the individualBad budget weather comes and goes. We need and can develop better mechanisms to respond in bad times that don't endanger people's community placement



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- ❑ SLS is not always the “bad guy” due to the cost of support. Agencies should not feel like at any moment SLS as a chosen service will be pulled due to cost

Housing

- ❑ Making housing affordable and accessible without putting the consumer in a dangerous environment
- ❑ More options for affordable housing for people that have very specific needs for privacy (not apts) “good neighborhoods.
- ❑ A better system than Section 8 as part of the regional center
- ❑ Availability of deeply subsidized and accessible housing
- ❑ Balance the desire for the closest match to ideal support with the need to get people into places where they are safe (physically and emotionally) ASAP
- ❑ Need affordable housing

Forensic Issues

- ❑ When regional centers don’t support diversion what happens to the consumers?
- ❑ Where are they placed?

Consumer Direction

- ❑ Consumers should be included at the policy making/setting level consistently
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