

**INCREASING INDEPENDENCE
WHILE LIVING AT HOME**

A Presentation by
Michael Pinkerton Associate MFT
ILS Director at Integrated Community Services

WHAT THIS TRAINING WILL COVER

- Summary of my background
- What is required to build independent living skills while living at home
- Why it is difficult to build living skills at home
- Going into more depth about six particular difficulties
- Addressing these difficulties with some suggestions and fixes
- Working through an example of creating a plan
- 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

BUILDING INDEPENDENT LIVING SKILLS AT HOME

- Requires a multifaceted approach
- Requires directed intention (and limited action) on the part of the parents
- Can often be done more effectively with the help of an outside party (therapist, life coach, advocate, Regional Center ILS provider or some combination of these)

AS A FAMILY THERAPIST AND THE DIRECTOR OF AN ILS PROGRAM, I SEE TWO SIDES TO THE WORK

CREATING A PLAN TO DEVELOP CERTAIN LIVING SKILLS

- Builds specific skills that are necessary for increased independence
- Gets child and parents on the same page
- Set up appropriate incentives, if needed
- Should be time limited

FINDING THOSE THINGS THAT GET IN THE WAY OF DEVELOPING AND IMPLEMENTING A PLAN EFFECTIVELY

- Ways of communication in the family often can be positively altered to support the plan
- Interactional processes often can be identified that are demotivating for children and frustrating for parents
- Reality checking can be provided by having an outside observer give feedback

DEVELOPING INDEPENDENT LIVING SKILLS IS VERY HARD WHILE LIVING AT HOME!

- No drive/need to learn the skills
- Children don't listen/take instruction from parents
- The demotivating skills gap
- Familial patterns are not typically organized around children developing independence
- Very rarely do families have the time, knowledge, or experience to build independence
- High levels of frustration within the family tend to get in the way of developing a new process

REASON #1: LACK OF NECESSITY

- When living with parents, it is typically not necessary to develop these skills
- This is a problem in all households, but is often exacerbated when a child has a disability

Does the environment at home create any need or impetus for the child (including the adult child) to develop living skills?

REASON #2: THEY WON'T LISTEN TO ME

- It is extremely difficult to teach your own children
- This is a problem for almost all parents I have come across
- It is a mystery why this is the case, but it is common in most families

I have some recommendations later for how to deal with this

REASON #3: THE SKILLS GAP

- It is extremely difficult for a developmentally disabled person to complete tasks when others in the home can complete the same tasks more quickly, more efficiently, more thoroughly, and without help.
- This is a problem specific to individuals that:
 - Are slow to learn
 - Have physical or mental difficulties that make task completion slower
 - Have physical or mental difficulties that make task completion not as thorough
- Think about it: When you go out to play tennis, do you want to face Monica Seles every time?

I have some recommendations later for how to mitigate this

REASON #4: FAMILIAL PATTERNS NOT ORGANIZED AROUND PROMOTING INDEPENDENCE

- Family patterns typically develop around necessities
 - Getting things done (efficiency)
 - Making enough money
 - Keeping the peace
 - Minimizing work
 - Maintaining safety – so building independence can run counter to this, creating anxiety in all parties, and standing in the way of building any kind of independence

This tends to create habits that do not leave the space needed for promoting independence.

REASON #5: LACK OF KNOWLEDGE AND EXPERIENCE IN HOW TO BUILD INDEPENDENCE

- Your first child tends to be a test case where you learn a lot
- If your second child is much different than your first, it is hard to apply the knowledge from #1 to #2
- So, unless you have multiple children, it is hard to get experience raising children
- Raising a child with a disability has its own set of complications
- It can be very hard to fathom what independence might look like for your child with a disability
- It is more daunting, scarier to consider independence when your child is at risk in a variety of ways

REASON #6: HIGH LEVELS OF FRUSTRATION IN THE FAMILY

- Living with others over time can generate a high level of frustration with their perceived shortcomings
- Being quick to frustration is a difficult setting for teaching/learning to occur
- Being quick to frustration also can lead to both parent and child giving up quickly

PLEASE NOTE: THESE PROBLEMS ARE NOT AUTOMATICALLY SOLVED BY MOVING OUT

- Each of these problems can (and often DO) happen in an SLS home or a group home if staff is there all or most of the time!

DEALING WITH REASON #1: THE LACK OF NECESSITY

- Is it possible to remove yourself from any task that your child wants to complete so that for your child to receive the benefit your child must complete the task? Such as making a favorite food. This creates necessity.
- Can you require tasks to be completed to get allowance, gifts, privileges? This adds necessity, especially if you let your child buy something that you wouldn't normally allow.

While both of these suggestions may seem simple, they are quite effective, AND they are difficult to implement effectively.

DEALING WITH REASON #2: THEY WON'T LET YOU TEACH THEM

- Is it possible to remove yourself from the room when your child is completing tasks?
- It is too tempting for parents to provide constructive criticism
- Anxiety for safety reasons can cause a lot of comments
- It can be a compulsion to do the work after them, which is a motivation killer for them

While you may think that you can overcome these pitfalls, my advice is to show a few times and then let them do it with you out of the way!

**DEALING WITH REASON #3:
THE SKILLS GAP**

- Is it possible to remove yourself from the room when your child is completing tasks and make it clear that you are NOT available?
- Can you purposely slow down, potentially act like you are unsure, or in other ways reduce the skills gap? Our trainers regularly do this and it can help.
- Use Most to Least Prompting methods

**DEALING WITH REASON #4:
CHANGING FAMILIAL PATTERNS**

- It typically requires an outside observer (such as a family therapist) to locate patterns of interaction that interfere with cultivating independence
- Usually, such patterns will need to be identified, pointed out to family members, and alternative patterns will be discussed, and agreed upon
- Follow-up must occur to discuss any new issues that have come up, and to encourage sticking with this new way of handling things
- Such patterns are habitual, so much effort may be required even to make a minor change!

**DEALING WITH REASON #5:
LACK OF KNOWLEDGE IN WHAT IT TAKES
TO BUILD INDEPENDENCE IN THE HOME**

- Education should be provided about developmental processes
- Concepts such as individuation and differentiation should be explained
- The current situation in terms of feelings, behaviors, and actions should be considered in light of this information

**DEALING WITH REASON #6:
HIGH LEVELS OF FRUSTRATION**

- Many times, frustration is unacknowledged (at least by one or two parties), which does not help improve things
- Once voiced, sources of frustration can be addressed and lessened meaningfully (even a little less frustration can be meaningful)
- Frustration also can be a natural byproduct of the living situation, and this can sometimes be altered in some fashion

**THE KEY TO PROGRESS IS HAVING A
PLAN (AND STICKING TO IT)**

- Creating a plan and timeline for how your child will learn independent living skills is essential
- Your child must be motivated by something within this plan (e.g. the possibility of driving, having more money to spend, having more freedom to spend, etc.)
- The plan should be limited to a single goal area
- The plan will function best if time limited

**PLANS MUST BE TAILORED TO
ABILITY LEVEL**

- The example I am using is a combination of individuals, a few young people, one with autism, one with CP, and one with a non-specific intellectual disability
- A plan can be created for nearly any ability level, but plans will differ greatly based upon that level
- For example, individuals with different ability levels need varying amounts of support
- An individual who will likely need to cook or engage in other activities with support, will require goals that include that support

EXAMPLE CASE STUDY WITH PLAN

- Wants son with DD generally to become more independent; one example is to learn to use the bus to go to local grocery store and purchase some items for the family
- Son is anxious, doesn't particularly like the store, prefers to stay home and play video games
- Wanting him to do this has not propelled him into action
- Loves to eat gluten free frozen pizza, not a family favorite
- Enjoys certain snack foods deemed acceptable by parents, but not enjoyed by anyone else in family
- Currently power struggle around video games, don't want him buying violent type games, R rated type games, will not allow them in the house
- Dad fed up with his lack of wanting to develop skills, mother concerned about his anxiety

DEVELOPING THE PLAN

PLAN MUST ADDRESS NECESSITY, WHO WILL TEACH, & SKILLS GAP

- #1 Necessity: Refuse to buy frozen pizzas or favorite snack foods, let him know that he can get these items when he goes to the store
- #1 Necessity: Find a video game that you would not normally let him buy (but is the most acceptable to you), and let him earn points to buy it by going to the store
- #2 Won't be taught by you: Have older sibling, school mate, "cool" relative, ILS provider, or advocate teach the skills
- #3 Skills gap: Not as critical on this type of skill, but taking a back seat by doing own shopping, stepping out for a minute, etc. can help

POSSIBLE ROADBLOCKS TO DEVELOPMENT/IMPLEMENTATION

- Being unable to settle on a particular goal
- Not buying his favorite foods feels mean
- Not willing to compromise on the video game issue
- Too worried about potential dangers as he becomes more independent
- He refuses any idea or suggestion, appears to shoot everything down
- Difficulty taking the time and the effort to stick to plan
- Can't locate someone to do the teaching
- Helper ends up enabling

NEGOTIATING THE PLAN

- Discussed the fact that having to work for something is not "mean" and can help build independence
- Worked out a list of video games that fall into the violent genre that feel better for the parents and that he would be excited to play
- Found that he would accept his sister to instruct him and she was willing to do it on her summer break
- Provided some resources for her around prompting
- Limited the plan to learning to grocery shop over a 3 month period
- Worries about the eventuality of him going on his own were shelved for now, since his competency level will change as he practices
- When he refused suggestions, parents just noted that they would not be buying those foods for him, and he came around
- Follow-up meetings allowed for reminders on the importance of the plan and helped them stick to it

PLAN

- "I agree to learn to grocery shop independently by August 31st, 2020."
- Trips will be twice a week.
- During each trip, two favorite foods can be picked in addition to purchasing the other items on the list.
- Parents agree that no other favorite foods will be purchased while the plan is in place.
- After each trip, parents will be set aside \$2 for video game fund. When goal is reached, the money can be used toward purchase of Assassin's Creed or Modern Warfare, though parents would prefer selection of alternative non-violent game.
- Everyone agrees that older sister will implement the plan when she is home from college
- Older sister agrees to research Most to Least Prompting model

IN SUMMARY

- Building independent living skills at home, while difficult, is possible
- Pick an achievable goal
- Make sure that everyone is motivated to achieve the goal
- Find incentives if needed
- Create a simple plan to reach that goal
- Deal with any roadblocks
- Stick with the plan until the goal is reached
- If you want help or are stuck, seek out an ILS provider, therapist, life coach, advocate, or some combination of these

Q+A
