TRANSITIONAL HANDBOOK FOR YOUTH WITH DEVELOPMENTAL DISABILITIES

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ABSTRACT

TRANSITIONAL HANDBOOK FOR YOUTH WITH DEVELOPMENTAL DISABILITIES

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I am an intern at Redwood Coast Regional Center (RCRC). While I am interning at RCRC, I will construct and produce a Transitional Handbook for youth with developmental disabilities (DD). Currently the area that Redwood Coast Regional Center covers does not have a handbook for youth. To compile the needs assessment for a handbook, I will use inter-agency documentation, other RCRC county handbooks, and public websites. I organized a focus group that consisted of RCRC contracted service providers ages 18 and over. The focus group, with the help of the participants, supported my finalization of the Transitional Handbook. The focus group determined what the best services and skill sets are for transitional-age DD youth to prepare for adulthood. I submitted the final Transitional Handbook to Redwood Coast Regional Center for approval. Once it is approved, RCRC will distribute the handbook to its transitional age (14-18) clients.
ACKNOWLEDGEMENTS

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INTRODUCTION

The proposed research project is titled “Transitional Handbook for the Developmentally Disabled Youth.” As social workers, we know that the developmentally disabled population is a minority in this country that has been discriminated against and ignored. It is only in the past 50 years that the developmentally disabled (DD) have been represented in civil rights and policy action. According to the Department of Human Services (2013), the DD movement started in 1969, when John F. Kennedy enacted a panel on mental retardation. In this panel, they discussed the “exclusion of the DD population from schools, communities, and many spheres of public and private life.”(AIDD, 2013) In 1975, the Developmentally Disabled Assistance Bill of Rights Act came into law. This act provided:

- The right to appropriate treatment, services, and habilitation in the least restrictive setting that maximizes developmental potential, and specified that public funds should not be provided to any residential program for people with developmental disabilities that conflicts with, and does not meet, the minimum standards for nutritious diet, medical and dental services, prohibition of physical restraints, visiting rights for relatives, and compliance with fire and safety. In 1978, four priority service areas were established: case management services, child developmental services, alternative community living arrangement services, and non-vocational social-developmental services (AIDD, 2013).

This area of research became apparent when I started interning at the Redwood Coast Regional Center (RCRC) in Eureka. The agency serves individuals of all ages, from babies to older adults, with developmental disabilities. The service coordinators in RCRC supply referrals to job assistance programs, work programs and other resources.
The transitional-age (14-22) clients with whom I have been in contact so far have said that they would like to have more self-advocacy, meaning that they would like to be able to be in control of their own decisions, including decisions about their care. I have noticed that there are no handbooks or guides that assist transitional-age individuals about services that are offered to DD youth when they turn 18, in order to help them live independently and develop life management skills. Without a guide to assist them, youth have to rely on family members or case managers. With a handbook for DD transitional-age youth, they would have more control of how they want to pursue their independence.

The result of the finalized handbook was the beginning of a long process that will allow my handbook to go into circulation at RCRC. RCRC management approved my handbook, but it will have to go through the Board of Directors to get permission to begin circulating the handbook to transitional-age clients. If the Board of Directors does not approve it, then the management of RCRC will revise it with my permission and resubmit it to the Board of Directors.

**Purpose of study**

Creating a transitional handbook for developmentally disabled (DD) youth is significant to the field of social work because conducting research in improving services for the DD will help the agencies that cater to this population to work more efficiently and prepare youth with DD for adulthood. Having a handbook for the clients will promote self-efficacy and self-determination, which is one goal that RCRC has for its clients. DD individuals will develop self-determination by being their own advocates in
developing their transitional life plans. The 14-22 age period is a difficult time of transition in any demographic. With an added developmental disability, it becomes an even more tremendous challenge. The help of a guide will lead them into adulthood, with a transition that is easier and that has a more attainable chance of success.

**Stakeholders**

The stakeholders in this research project are the case managers of RCRC, transitional-age youth who are clients of RCRC, and service providers of RCRC. The families and DD individuals are the beneficiaries of this research project. Once the final handbook is distributed, the handbook will be in the hands of the clients. One of the purposes of the handbook is to encourage clients to become more aware of the choices that are available to them during their transition to adulthood, thus promoting self-advocacy and self-advocacy. This result in turn will help the service providers and case managers’ job become more efficient because clients will know already what services are available to them, without assistance from service providers.

**Research Questions**

The research questions for this project are:

- How will the creation of a handbook assist youth with transitioning to adulthood?

- What services and skills are the most helpful for transitional-aged youth with DD?
• How can these services be more accessible to transitional youth with DD?
REVIEW OF LITERATURE

The purpose of my literature review is to provide a background of previous research on guiding youth with developmental disabilities towards their transition to adulthood. This has also helped me conduct and finalize my own research project. I researched which methods are most effective in guiding youth with DD to adulthood. I also conducted a search on books or handbooks that provide education to parents about transitioning youth with DD to adulthood. Finally, I consulted websites to help me with my initial needs assessment.

In a study by Turner (2007), he inquires how teachers can make the transition to adulthood easier for students with learning disabilities. During the study, the researchers developed theories of transitions for DD individuals. Some common sentiments that they found were a sense of being lost, depression, anger, and frustration. The students that they interviewed were frustrated that there were no services to help them transition after high school. After high school, according to Turner (2007), the students felt that they were “pushed into the deep end of the pool” (p.225). The conclusion of the study showed that high schools should adopt transitional counseling and education about services that can help achieve it. My research project will build on that study by making a handbook in which DD high school students can read about services and life skills while to help them with the transition. I intend for the handbook to be a way of preparing DD youth for the transition to adulthood before they leave high school.
In the study by Williams (2005), he examined the problem of the underrepresentation of students with disabilities in colleges as well as possible solutions to this problem. They used an impact evaluation study to determine their finding. The conclusion was that transitional programs in high school are paramount for DD youth and that disability centers at universities need to be more proactive about presenting their services to high school students. The handbook in my project will include college preparation skills, learning resource centers in universities, and other resources to present to DD youth the idea that college is an option.

In the study by Zionch (2011), he proposed that life, social, job and other skills be formatted into a digital handbook. The researchers note that youth rely on technology in their daily life as well as in their education. The question they raise is, “Why not use technology to serve the developmentally disabled population?” They propose creating an individual DVD for each skill, such as money management, jobs, and house cleaning (Zionch, 2011). From a realistic standpoint, producing a handbook first for youth is fundamental because it can become a foundation for future projects, such as DVDs or braille handbooks.

In the dissertation by Cagle (2006), the author writes about self-determination theory and its role in transitioning youth with developmental disabilities towards adulthood. She explains that it was introduced in the field of special education in the 1990s and that it encompasses four aspects. The four aspects are creativity, assertiveness, pride self-advocacy, and self-actualization (In order to be successful, a
student must achieve these aspects. During the construction of my handbook, I will have references to vendors that will help them actualize their potential to lead a successful life.

**Conceptual Framework**

I am using self-determination theory as my conceptual framework for this project. According to the Self-determination Theory website (2013), “It is concerned with supporting our natural or intrinsic tendencies to behave in effective and healthy ways” (Self-determination theory, 2013, np). The transitional handbook for youth with developmental disabilities will help clients find their self-efficacy and self-worth. The goal of this project is for clients to be self-starters is conducting the next chapter in their life.

The work of Steere, Rose, and Cavaiolo (2007) targets families with developmentally disabled children. The book's goal is to show that developmentally disabled youth can successfully transition to adulthood. The authors make their case by presenting two longitudinal case studies they have done, one of a youth with a severe disability and one of a youth with a mild disability. The practices Rose and Cavaiolo include are person-centered thinking, transitional vocation, Individualized Education Plans (IEPs), service providers, and others. During the case study, the authors implement effective practices to help the youth with their transition. This method illustrates to the readers what methods are most effective with developmentally disabled population. While a handbook for the families of developmentally disabled children and youth is an
important resource, I intend to do my transitional age handbook specifically for the youth to read. That means my content will focus more on youth than on older adults. The handbook’s content will emphasize services that youth are concerned about, such as graduating, life goals, and balancing school and career, for example. I will make the content more accessible to readers with developmental disabilities by having larger print, picture bullets, and check boxes.

The informational and resource guide on transition to adult education written by the Department of Education (2007) focuses on preparing high school students to transition to adulthood. This resource guide focuses on the Individuals with Disabilities Education Act of 2004 (IDEA). This act allowed children and youth with disabilities to have the right to free public education and transitional services to adult living until the age of 22. Students in special education have yearly individual education plan (IEP) meetings, which entail going over the student’s individual education goal. According to IDEA (2004), starting at the age of 16, the yearly IEP meeting consists of transitional planning. Transitional planning entails postsecondary education, vocational education, integrated employment, continuing and adult education, adult services independent living, and community participation (Department of Education, 2007). My handbook will include information on how to prepare for adulthood while still in high school, and I will also list vendors and resources to help to prepare for adulthood outside of a school setting.
The tips for transition compiled by the University of Kansas Department of Special Education (2009) focus on transition planning before youth with developmental disabilities turn 18. This resource guide focuses on preparing for adulthood during the early stages of adolescence. They also focus on making sure teachers put forth self-empowerment and self-determination in the transitional planning of their students. This handbook’s goal is to give power and control back to the students, whereby they would have a say over what they want in their lives. In my handbook, I will include self-empowerment theory and gear my handbooks to a younger audience, in order to help them begin preparing even earlier for adulthood.

On the Department of Developmental Services Consumer Advisory Committee (2002), the members encompass people with developmental disabilities. The committee has compiled a booklet that teaches RCRC service coordinators about what choices committee members want to make in their life. The committee interviewed 400 of their peers in California. The results of the interview showed that they want to make more of their own choices with regard to money, housing, transportation, relationships, personal care, and personal freedom. The interview also showed that consumers also want staff to be more aware of how to educate people with developmental disabilities about the legal rights they have. My handbook’s goal is to give the decision-making process back to the consumers. I am going to include categories such as housing and money to make the handbook as well rounded as possible.
Synthesis

From my literature review, it is apparent that there is a need for better resources for youth with developmental disabilities in order to help them achieve success after high school. There is a recognition that self-determination is an important part of helping youth with DD achieve their goals. The literature also shows that the transition toward adulthood for people with DD is a hard journey, and the more preparation about their options, the better chance they have of being successful.
METHOD

The project started with a needs assessment to construct the rough draft of my handbook and to answer my research questions. The needs assessment entailed going through RCRC documentation. I looked at other RCRC county handbooks, government websites, and secondary data from RCRC clients. My research method is qualitative, as my focus group adopted this methodology. In the focus group, after my rough draft of the handbook was constructed, I mailed the hard copies to the participants two weeks ahead of time before the focus group so that they were better prepared. They brought the hard copies with them to the focus group. The focus group was a one-time event that had eight participants. The participants were Redwood Coast Regional Center contracted service provider employees ages 18 and over. The interview was unstructured. I asked my research questions. Besides my research questions, I asked, “what should be added, removed, or modified to the handbook?”

The focus group took an hour and a half. The focus group took place at RCRC. I audiotaped the focus group using the tape recorder in my iPad, which has a passcode. I mailed the consent forms to their offices, but as back up, I had extras for the participants to sign before the start of the focus group. I gave them an overview of the project and explained that the information received in the focus group will be in my final report and be in the Humboldt state Library. To keep anonymity, the participants had nicknames that I had assigned to them earlier. We used these nicknames throughout the focus group, and I kept reminding them to use them during our time together. I did not use
their real names or the title of their agency in my report or during the focus group. Every
participant consented to the use of a tape recorder. I used an electric device with a pass
code that only I know. I also reminded them in the beginning that they are free to skip a
question or leave the room and take a break, and also that participation in this study is
voluntary and they can leave anytime.

**Participant recruitment**

At my internship at Redwood Coast Regional Center (RCRC), my agency
supervisor and I recruited key contracted RCRC service providers, who work with
transitional-age youth (14-22) with developmental disabilities. The employees were 18
and older, and so they were able to consent. I recruited the contracted service providers
from vendors in the service categories of vocational training, day programs, residential
care, supported living and financial (payee) services. I e-mailed potential participants to
recruit them for participation in my study, which ended up including eight participants.
Once individuals had agreed to participate, I mailed them an informed consent form.
After they had signed the consent form, they mailed it, using the return envelope I
provided, back to my RCRC office. I sent the informed consent forms in advance so that
the participants would be prepared for the focus group. In addition, this gave them the
option to decline participation in advance before the focus group. I then notified the
participants via e-mail of when the focus group would take place.
**Data Gathering Technique**

The data gathering technique included a needs assessment, described above, in which I was able to construct the rough draft of my project and to answer my research questions. In the second data collection, there was a focus group, in which we were able to read over and analyze the rough draft of the Transitional Handbook. Based on the responses from the participants of the focus group, I was able to finalize the handbook for distribution.

**Data Analysis Method**

The research methodology was a qualitative meta-analysis. For my first data collection, I used a needs assessment to compile a rough draft. For my second data source I conducted a focus group in which I used snowball sampling to choose my participants so that I was able to select a well-rounded group that represented the DD community. For the focus group, I audiotaped the session. I was able to base my findings on the needs assessment and focus group by utilizing a meta-analysis method. Through these qualitative methods, the research produced a finalized transitional handbook for youth with developmental disabilities.

**Benefits**

I did not compensate the subjects monetarily. However, with the help of the finalized transitional handbook, the participants’ clients will gain self-efficacy in transitioning towards adulthood.
Limitations

An important limitation is the period for the research project. I will not be able to track and observe the long-term effects of the transitional handbook. As a way of addressing this limitation, I suggested that RCRC continue to track the progress of the handbook and impact that it is having upon their transitional-aged clients.

Potential Risks

Potential risks are that confidentiality could be broken. In order to maintain confidentiality, participants used nicknames which I assigned them for the focus group. Another risk is that the focus group can take time away from participants’ clients.

Risk Reduction

I did not use participants’ real names or the title of their agency in my report or during the data gathering. Every participant has consented to the use of a tape recorder. I used an electronic recording device with a pass code, which only I know. I also mentioned in the consent form and at the beginning of the focus group that the information obtained in the focus group is in my report and will be made public at Humboldt State University. This is why I used nicknames and did not mention the title of the participants’ agency.

To ensure that the focus group is as short and efficient as possible, I sent participants a hard copy of the handbook draft beforehand, so that the participants would have already read the material and would not have to read the handbook in the focus
group. This shortened the length of the focus group. I also had a break in the middle of the group. In addition, they had the ability to pass on a question if they did not want to respond. I also reminded them verbally and in writing that participation in this study is voluntary and that the participant can leave anytime.

**Ethical Considerations**

There was less of an ethical dilemma because the participants are adult social service agency employees. However, I still made provisions for protecting their privacy. I collected informed consent forms from each of them. In the focus group, I explained the confidentiality procedures that the study followed. I coded the focus group findings to protect potentially identifying information, and the research information was locked in a file cabinet to protect it from unauthorized access.

**Summary**

The research project that I produced will be of benefit to the community. This handbook will help Redwood Coast Regional Center’s transitional-aged clients. I hope that the outcome of the handbook will help better prepare youth with developmental disabilities to find self-determination in making their own choices toward their transition towards adulthood.
RESULTS

Needs Assessment

While compiling the rough draft of my research project, I used resources from my literature review and other handbooks from other regional center. While deciding on how to lay out my handbook in a way that would be most accessible to the readers, I decided to split the handbook into five parts. The five parts of the handbook will be college/work, housing, financial, safety, and transportation. In each section, I will have a checklist of important tasks that individuals should complete before turning 18. In addition, there will be a reference page after each section that will include websites that will be helpful to the reader in researching options for adulthood on their own.

College/Career. I decided to make the title different from other county handbooks by having a catchy title instead of a generic one. My title is “What next?” I believe this will catch the readers. This title also conveys the feeling of every high-schooler when they graduate. In the college and job section, I used an example from Transition to Adult Living: An information and resource guide (Sicile, 2008). The concept that I decided to use in the beginning of my handbook is the person-centered thinking questionnaire. The person-centered thinking questionnaire is a communicative tool that RCRC uses with our clients. Person-centered techniques focus on giving more power to the clients and what they want from us, the service coordinators of the RCRC. This
technique is relevant to this handbook because I am using self-determination in the handbook. The main point of this handbook is to give the power back to the clients, in order to empower them to make their own choices in their lives. Some of the questions that I am putting in the handbook include, “What things make me happy and sad?” “What new people would I like to meet?” “What things have I learned recently?” and “What new things would I like to do and learn?” Putting this questionnaire in the beginning of the handbook will give the reader an opportunity to brainstorm about what they want after high school. I also ask questions about what their interests and hobbies are and whether they can turn these interests and hobbies into a career. However, I also give the readers a reality check by asking them what the requirements to achieve their dream are and what kind of finances they will need to get there. I also give them many options besides college. I write about trade/vocational school, workday programs from a RCRC vendor, and even AmeriCorps.

**Housing.** In the housing section, I am emphasizing the many options that are available to RCRC youth. One of the options is independent living but with supported living services. Supported living services is when an employee from a contacted vendor of RCRC spends a number of hours that they have agreed upon to help the RCRC tenant with any tasks that will help with his or her independence. There is a wide range of eligible tasks, including helping with chores, grocery shopping, bills, doctor appointments, and others. This is a great alternative for a young adult with a developmental disability. Rather than staying with her or his family, they can choose to
live independently, but they can learn from my handbook about the option of support from RCRC.

Another thing that I am emphasizing in my handbook is safety. I believe safety is the most important aspect when starting to look for a new place. I feel this is so important that I will devote a whole section to safety. I mention on my checklist of what to look for when looking for housing that safety, affordability, and the environment surrounding the complex are most important. As young adults, this population has very little money. Again, I provide clients with a reality check by asking them to consider what they can actually afford. In many places, there is the option of section 8 for developmental disabilities, but that can take up to 8 years. However, in some counties that have regional centers, some of them offer rental subsidy programs.

I also ask questions about what kind of community they want to live in. For example, do they want to live in an area where many other young adults live? Do they want to live near a park, or some other outside venue where they can exercise or take walks safely? Is it near a bus stop? Is it near places to eat? Near a community college? Does the client want to be near his or her family, as the family can feel secure that their child is close by?

**Transportation.** Transportation is an important factor for youth with developmental disabilities, as many people in the target audience for my book cannot drive. In my transportation section, I have focused my attention on the bus system. The transportation ended up overlapping with the housing section, because when a youth decides to start looking for housing, it is crucial that transportation is accessible near
where they live. For example, I mention to check all the bus stops near where the client is going to live, to make sure that he or she can go to work, to visit friends and family, and to doctor appointments easily.

I also wrote that the reader should practice taking public transportation while still in school. In the reference page of the handbook, I linked the reader to the public transportation site of the Eureka, McKinleyville, and Arcata systems, letting them know that they can start taking the bus to school and to visit friends.

I also mention that there is a way for some developmentally disabled individuals to get a driver’s license by using adaptive equipment. For example, there is adaptive equipment that can help a person if one part of their body is weaker than the other. There are adaptive wheels, gas pedals, and much more that I mention. To take the permit test, an applicant can take an audio test rather than the written one. I also mention using a bicycle, especially if work and other destinations are close by. Another part of my transportation that overlaps with my housing section is that I tell the reader that it is a bonus if destinations are close proximity to where you live, because another option is to walk to places. I also mention that if the reader has family members or friends that are willing to drive him or her, this is another option for getting around.

**Finance.** I decided to do a finance section because for young adults, especially those with developmental disabilities, money is a constant reality in their lives. Managing money is hard for everyone, so I decided to put a sample budget plan in my handbook. I found a monthly budget plan that breaks down what one spends in a month.
For example, there are sections to write down what one spends on food, gas, utilities, rent, entertainment, and other categories. I also wrote about the envelope method. This method requires the person to put money in a few envelopes. Each envelope represents a part of the person’s monthly budget. For example, there will be an envelope for entertainment. If that envelope has $100 in it, the person cannot spend any more than that.

I also mention SSI and SSA, as these two incomes are very important to the audience for my handbook. I tell the reader to apply for SSI before the age of 18, as it can take a long time to enroll. I also mention the Ticket to Work program, which is part of SSI. The Ticket to Work program helps individuals with SSI go to work.

These are all the sections I did for my needs assessment of the rough draft of the handbook. I believe that putting my handbook in sections will be more accessible to the targeted audience. When I have completed the final handbook, I will have a table of contents of the sections. That way, a reader can flip to a section that is pertinent to them. My knowledge of transitioning to adulthood with developmental disabilities was paramount because I have lived through it. This was an advantage, as I had many resources and suggestions that were in my “memory bank.” However, I made sure to research on other resources, because every reader is going to have their own life experience of living with developmental disabilities. I kept that in mind when I did the needs assessment. This was a good rough draft to bring to the focus group, as they will have enough information to give quality feedback.
I answered the research question, “How will the creation of a handbook assist youth with transitioning to adulthood?” through my literature review and needs assessment. There have been other Regional Center handbooks for transitional-age youth that have been successful in aiding youth with developmental disabilities with upcoming adulthood. In addition, through my research, I have found that youth with DD need assistance with emerging adulthood. If clients of RCRC had a guide that would allow them to embark on this adventure with small goals, this handbook would assist the clients and their families in doing their own research on what services would be most suitable for their child. This needs assessment was a significant help to producing the rough draft of my handbook and to answering some of my research questions. Now, my focus group will help me finalize my manuscript and also to ask my research questions to professionals in the developmental disability community in Humboldt County.

**Focus Group**

The focus group is my second data collection, in which I utilized a qualitative method to conduct my research. I scheduled the focus group at RCRC for an hour and half. There were eight participants.

**Housing.** During our discussion of housing, the participants agreed that that I needed to expand on the housing section. Participant A stated that I “should delve more into what types are available for people with developmental disabilities.” The types of
housing we formulated in the group are foster housing, SLS (supported living services), IHSS, group homes, and care homes. Participant A stated to “just write small descriptions of each of the type.” This is good feedback, as these descriptions of the housing give the reader options into what type of housing they want to live in.

Participant A also suggested adding transportation under my list of the most important qualities of house searching, which include safety, affordability, and social environment. This feedback makes sense, as accessible public transportation is crucial for a person with a mobility disability. Participant A and Participant B mentioned to add low-income housing options in conjunction to Section 8. The focus group pointed out to me that the Section 8 waitlist can be as long as 8 years, as opposed to low-income housing, which can be available to housing applicants in the present.

**College/Jobs.** Many participants mentioned to me that they felt that this handbook would benefit mostly higher-functioning RCRC clients. Participant B stated that 75% of her clients would not be able to read this handbook by themselves. That said, the focus group suggested that, when RCRC distributes this handbook to clients, that families of the clients help them in filling it out. That is why I decided to write a disclaimer in the front of the handbook to tell the readers to go over the material with a family member, school counselor, or RCRC service coordinator.

Participant E mentioned that the SATs should not even be mentioned in the handbook, as most of the clients who do decide to go to college will end up going to community college, adult school or vocational school, so the handbook should focus more on those options. Participant A mentioned that walking tours of community
colleges and vocational schools during high school are critical to youth in their decision-making of what option they want to pursue. Participant E also mentioned that I should touch upon the GED process, as some of RCRCs clients will not get a diploma, but may want to have a certificate. Another area to focus on in the school section of the handbook is to mention the IEP (Individualized Education Plan) and how the reader can be more involved in the process. Since my goal with this handbook is to promote self-efficacy, then the clients should have a more active role in their IEP meeting by being present at their meetings and preparing questions and goals that they want to talk about. Participant D mentioned that I should add the explanation of 504 Plan. The 504 Plan is crucial to people with disabilities to have in order to continue to receive specialized services from college and other venues when they have aged out of the ITP (Individual Transition Plan).

These changes will allow the student to have more power in the decisions made in the IEP. Participant E mentioned that there is a YES assessment module online that specifically helps youth with disabilities “maneuver” around what career would fit best to their personality. Another suggestion that some of the participants mentioned is to add a sample resume that is already filled out so the reader has a template to work from.

**Transportation.** During our discussion of transportation in the focus group, Participant C mentioned to talk about help with transportation on campuses – specifically, to add that DSPS (Disability Student Program Services) has a service that will give rides to students with disabilities around campus. At HSU, Disability Services has a specific van that transports their students from class to class. In addition, in
transportation, Participant E stated that I “should look into specific programs that make adaptations to new drivers who have disabilities.” This way I can reference the programs in my handbook, so the readers can call them up. Another add-on that the focus group mentioned was that many of the clients of RCRC will not have driver’s licenses, but they will still need a card for identification purposes. So in my handbook I will mention California I.D., how to obtain it, and why it is important to have identification on yourself at all times.

**Finance:** The focus group discussed finance at length because money can be a tricky situation when SSI disability is involved. Participant A mentioned that I should add SSA as well as SSI, as many clients have SSA from their parents. Participant A said I should also mention the 2:1 formula of how SSI is impacted when a SSI recipient starts to work. This section would be crucial, as there are many SSI recipients, who fear going back to work because of the possibility of losing SSI. This is a myth and part of this handbook is to debunk it. To add to debunking the myth, I would add a calculator too that specifically aids SSI recipients in calculating their SSI reduction when working. Participant A also mentioned to add something about what a public guardian does. This is important because many clients of RCRC who are not intellectually capable of managing their own money have a public guardian. When I put a description of public guardians, I will also mention the special needs trust.

**Miscellaneous.** Participants D and E recommended a glossary of key acronyms that I should put in the beginning of every section. This add-on is crucial, as many clients of RCRC will not have knowledge of many of the acronyms I am putting in the
handbook – for example, it will be helpful to explain what SSI, SSA, DOR, and section 504 mean. Another suggestion that Participant C recommended is a small section on time management. I believe that a section on time management would be wonderful, because for young adults, it is hard to juggle everything. I believe in the section I will put a template of how to balance the many things that this client will be working on to achieve independence Participant C also recommended a couple pages in the beginning to mention “natural resources.” Natural resources are a support system that is already in place in the client’s life that can help them achieve their goal. For example, a trusted neighbor, school counselor, a best friend. In conclusion, the research questions include, “What services and skills are the most helpful for transitional-aged youth with DD?” and “How can these services be more accessible to transitional youth with DD?” were answered during my focus group. Participants talked about the skills and services in detail, addressing which ones would be most helpful and accessible to youth with developmental disabilities. We as a focus group decided that the skills that I would address in the handbook should be tangible, easily achievable, and not overwhelming. That is why we had groups or templates to have visuals in my handbook. The glossary and commotion list will make the work in the handbook tangible. When this handbook is completed, it will be a tool in the client’s toolbox, which will help them prepare for adulthood. I also decided to conduct the focus in an unstructured format, as this format will allow for more openness, feedback and constructive criticism.
DISCUSSION

The result of the project is a stepping-stone to helping improve services to transitional-age youth with developmental disabilities. During my needs assessment, I had many secondary data that helped me to construct a rough draft. I have received helpful feedback in my focus group that will allow my research project to help my client’s transition to adulthood. Through this whole process of collecting, constructing, and finalizing, I had support from the regional center and the developmental disability community. RCRC saw the benefit of this project for their clients, and so they invested in my research by helping me in the needs assessment. Management gave me secondary data, valuable advice and feedback. RCRC had always wanted to do a handbook, but management never got around to it. I believe and hope that this handbook will be valuable to RCRC clients, including youth with learning disabilities who struggle to “find themselves” after high school. In addition, a positive situation happened during my focus group that was unintended. Some of my participants have never spoken face to face together. This resulted in wonderful networking opportunities. Some participants were educating other participants about new programs, measures and rights that people with developmental disabilities have. However, during my focus group, I realized a big limitation that this project has, which is time.
Limitations

The main limitation of this research project was time. I will not be here for the end of this handbook. I will have left from Arcata before the board has approved it. I will have the final product and will have submitted it to RCRC, but it will still take a couple of months before it is ready for distribution. To rectify this problem, I am looking into locating another intern from the Office of Education to continue refining the handbook. The reason I am looking for an intern in the Office of Education is that he or she can modify the handbook for distribution to special needs students in the Humboldt County high schools. Because of this limitation, I recommend future researchers who will embark on a similar project to allot a sufficient amount of time to complete the project.

Outcome

This project was a help to the community and to myself as a social work student. This project will not just be a manuscript in a library, but it will be a resource that will help Redwood Coast Regional Center improve its client services. As for myself, this has been an educational experience, as I have absorbed a great amount of helpful information. All the knowledge I collected from my needs assessment and focus group will help when I work with developmentally disabled populations in the future. The
project was very collaborative, as everyone in my internship was passionate about this project and wanted it to succeed.

**Outcome for Social work**

This handbook is a contribution to the Developmental Disability community in Humboldt County. My project can be a basis for other agencies to formulate their own handbook, to help assist their clients. Any agency, we strive for our clients to achieve self-efficacy. A handbook developed according to this model could be useful for any population facing a major transition. For example, there can be a transitional handbook for recently paroled inmates who need help with acclimating back to their community. That is just one scenario where a handbook can assist vulnerable populations. My project can be a template for other agency has to help them manufacture their own handbook that they can tailor to their own population that they serve.
REFERENCES


What next?

Compiled and edited by:
Francesca Jenkins

Interned with:
Redwood Coast Regional Center
Acknowledgment

18 years old!!! An exciting time in our life, but can also be a scary and unknown time becoming an adult is a new chapter in our life, in which we have many paths we can choose from. Choosing what to do can be a hard road to conquer, but with this handbook you will have a tool in your toolbox that will help you navigate these unknown waters. This handbook will provide you with skills and necessary steps to practice before turning 18. Adulthood does not have to be scary, but an adventure where we find out who we are! Emerging adulthood can be an exciting time where we discover what our interests and passions are. In addition we can choose where we want to live, and people we want in our lives. You have the power to make these choices and be the captain of your destiny. Let's get started!!
Handbook tips

1. Take time to fill in your answers

2. Share this with your family, friends, and team members of IEP and IPP

3. Your plans for the future can change, so you can edit this handbook as many times you want.
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Appendix B

Informed Consent

Project: Transitional Handbook for Youth with Developmental Disabilities

To participants,

My name is Francesca Jenkins and I am the graduate student researcher in this study. I am a MSW student at Humboldt State University. During my production of the transitional handbook, my goal for my research will develop a resource that will help RCRC youth to achieve self-determination through self-advocacy during transition to adulthood.

Redwood Coast Regional Center (RCRC) serves individuals throughout the lifespan with developmental disabilities. Currently, clients of transitional age (14-22) does not have a RCRC official guide to assist them in transitions to adulthood. In my research project, I will create and produce a transitional handbook for RCRC transitional age clients that will collect information about these resources in a format that makes them more easily accessible.

You are invited to participate in a focus group that will entail reviewing a rough draft of the transition handbook, of which I will send you a copy beforehand. The group will recommend decisions on what life skills or resources should be added, cut or modified from the rough draft of the transitional handbook. The results from the focus group will help the researcher finalize the handbook for distribution.

This focus group will last approximately 2 hours and will convene once. The focus group will convene at RCRC during business hours. The focus group will be audio-recorded, if everyone consents to be recorded. If some participants do not consent to be audio-recorded, I will take notes during the focus group meeting. To ensure the safety of the content of the recordings in the focus group, the recorder will have a passcode and I will be the only one who knows this code.

There is no financial compensation for you participation, but the benefits of participating in the research are that the finalized transition handbook for youth with Developmental Disabilities will assist your clients to exercise their self-efficacy in transitioning to
adulthood. The handbook will help provide them with the tools and resources with a transition towards an easier, more attainable, and more successful transition. The risks of participating in this project are minimal. To maintain confidentiality I will assign nicknames to each participant to be used during the focus group in order to avoid participant’s real names appearing in the recording, and I will remind participants not to use the name of their agency in focus group discussions. I will describe confidentiality in the beginning of the focus group. Specifically I will explain that the information obtained in this focus group will appear in my final research report and it will be made public in the Humboldt state University Library. This is why I will use nicknames and avoid using the name of your agency in the report and during the focus group.

An additional risk is that the time blocked out for the focus group could be inconvenient. I will prevent this by setting up the focus group appointment a month in advance so that you will have sufficient time to adjust your schedule. I will also mail a rough draft of the handbook two weeks in advance, so that you will be able to read it in and prepare for the focus group.

Participation is this study is voluntary. You have the right to refuse to participate, withdraw from the study entirely, or skip any specific question(s) that you are not comfortable answering, at any time, without penalty or loss of benefits to which you are entitled. There will be a break in the middle of the focus group. I will also answer any question that you have about the study, the focus group or the questions that will be asked. Some of the questions that will be asked are: What services and skill are most helpful for transitional-ages youth? How can services be made more accessible to transitional youth with developmental disabilities?

If you have any questions regarding the study or this consent form, please contact me, Francesca Jenkins, the graduate student researcher for this study. I may be contacted at: (858) 722-9365 fcj12@humboldt.edu

If you have any concerns about this study, please contact the chair of the Humboldt State University Institutional Review Board for the Protection of Human Subjects, Dr. Ethan Gahtan; at eg51@humboldt.edu or (707) 826-5169

If you have questions about your rights as a participant, please address them to the Humboldt State University Dean of Research, Dr. Rhea Williamson, at Rhea.Williamson@humboldt.edu or (707) 826-5169.
The researcher’s faculty advisor contact information is Cesar G. Abarca, Ph.D. Dr. Abarca may be contacted at (707) 826 4552 or at cesar.abarca@humboldt.edu.

☐ I consent for the focus group to be audio-recorded (please check if you agree)

Signature

____________________________________

Date

____________________________________
Appendix C

E-mail Script.

Dear [name of potential participant],

My name is Francesca Jenkins and I am a Humboldt State MSW student currently interning at Redwood Coast Regional Center (RCRC). For my masters’ degree project, I am going to produce a transitional handbook for youth with developmental disabilities with RCRC’s approval. This handbook would greatly help your clients by providing them with a guide of resources and skills to help them transition into adulthood.

For my research project, will include a focus group composed of RCRC service providers from vocational training, day programs, residential care, supported living, and financial (payee) services, disability resource counseling services. The focus group will be a group interview and it will take about 2 hours and it is a one-time event. If you decide to participate in the focus group, you will be mailed a consent form to participate in the project and a hard copy of the rough draft of the handbook two weeks ahead of time.

In the focus group, you will collaborate on answering the following questions 1) what services and skill are most helpful for transitional -aged youth? 2) How can services be made more accessible to transitional youth with developmental Disabilities? 3. What could be removed, added, or modified from the rough draft of the handbook? To maintain confidentiality, your name and the title of your agency will not be included in my report. You will be provided with nickname to be used in the focus group. Your information will be kept confidential because the final report of the project will be made publicly available in the Humboldt State Library. Your participation would be greatly appreciated and will be helpful in the development of the handbook for transitional youth with developmental disabilities. Please reply if you would like to be included in the focus group. If you agree to participate, I will send you a consent form with more information by postal mail. If you have any questions or concerns, you can contact me by phone at (858) 722-9365 or by e-mail at fcj12@humboldt.edu . Thank you
Appendix D

Focus Group Guide

*Informed consent*
1) Explain confidentiality and how participants won’t be identified in report or recording.
2) Explain that they can skip questions, take a break, and leave at any time.

*Research process*
3) Ask research questions,
   a) What services and skill are most helpful for transitional-ages youth?
   b) How could services be made more accessible to transitional youth with developmental disabilities?

*Break*

5) What could be removed, added, or modified from the rough draft of the handbook?
6) Do you have any other suggestions to improve the content, form or topics (including services and supports) of the handbook?