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Data Collection & ABA Therapy with Disability & Child Welfare

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TSOCW 533: Integrative Practice II

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Abstract

This proposed intervention explains the need for both data collection on children with developmental disabilities in child welfare and how it will benefit future work, as well as a proposal of an evidence-based intervention using Applied Behavioral Analysis (ABA) therapy for children with developmental disabilities. The goal is to work towards improved outcomes for children with developmental disabilities and to create equity for these children in the child welfare system. The population focus of this project are children with developmental disabilities, specifically, children who are involved with the child welfare system. This will also include biological family and foster family with in-home services in order to either stabilize placement, prevent placement, or facilitate the child returning home. The theoretical frameworks at the bases of this intervention are intersectional feminist theory and anti-oppressive social work theory.

Introduction

This intervention focuses on gathering information on children with developmental disabilities in order to better understand issues of disproportionality and unmet needs so that child welfare systems can better meet the needs of children with developmental disabilities. While gathering data is an important first step to understanding the exact depth and breadth of the issue it is a long-term solution and intervention. For a more immediate intervention to address needs of children with developmental disabilities in child welfare, the Department of Children Youth and Families (DCYF) in Washington State Region 5 will contract with an Applied Behavioral Analysis (ABA) therapy provider to work with children and caregivers.

Needs Statement

Children with developmental disabilities when involved in the child welfare system are less likely to be returned to their birth parents, spend more time in care than neurotypical peers, and experience frequent placement disruption.

Goals Statement

The ultimate goal would be to improved outcomes for children with developmental disabilities and to create equity for children with developmental disabilities in the child welfares system.

Key Theoretical Frameworks

There are two theoretical frame works that this project is oriented with. The first is intersectionality. Intersectionality is a framework to understand how people's different identities intersect and connect for different modes of oppression and privilege. A theory and term originally created by Kimberlé Crenshaw when she was analyzing a lawsuit by African American women who were complaining of racist and sexist treatment by an employer. Intersectionality has been expanded on as a theory that analyzes and seeks to understand the relationship between different identities in society (McCann & Kim, 2017).

The second theoretical framework that will be used is oppression theory and anti-oppressive social work practice. Oppression theory is "primarily concerned with the social, political, and economic structures as well as the social and psychological processes that initiate, maintain, and enforce oppression." This theory focuses on the social work ethical commitment to social justice and being conscientious of how social workers can intentionally or unintentionally engaging in oppressive behavior. The central features of oppression that have been identified are privilege, domination, and exploitation (Robbins, 2017). By using both oppression theory and

intersectional theory, the experience of individuals with disability in our society can be understood on multiple levels of macro, meso, and micro as well as examining it through an intersectional lens that disability may not be the only identity through which an individual experiences oppression.

These theoretical frameworks are important to remember when working with individuals with disability as disability is not their sole identity through and it is not the only identity through which they might experience oppression or privilege. It is also important to keep in mind that there is already a huge amount of racial and class disproportionality in child welfare and there is a need to understand how race and class also intersect with disability in child welfare.

Objectives & Indicators

Outcome 1: Creating data tracking system for DCYF internal database FamLink

Indicator 1a: After 6 months an accrual of data is noticeable.

Criteria to achieve indicator 1a: There is enough data collected by CHET and CFWS workers after 6 months to start to identify trends in the data.

Indicator 1b: After 1 year enough data is collected to be able to do statistical analysis.

Criteria to achieve indicator 1b: Statistical analysis of the data begins to show areas for need, improvement, or inequity.

Outcome 2: Contract set up with ABA in home therapy service providers in Pierce County.

Indicator 2a: After a year 20 % fewer children with DD will be in foster care in DCYF Region 5(Pierce and Kitsap Counties).

Criteria to achieve indicator 2a: All families and children who qualify and are involved with DCYF will be referred for services.

Indicator 2b: After a year there will be a 20% increase in children with DD returning home in DCYF Region 5(Pierce and Kitsap Counties).

Criteria to achieve indicator 2b: Pre-referral to ABA services data and information will be collected and post-return home and after services survey of families will be collected.

Intervention

Background Research

Studies have shown that children with developmental disabilities are overrepresented in the child welfare system compared to their typically developing peers. Child protective services systems serve a high number of children with developmental disabilities (Shannon 2011b) and it is estimated that two-thirds of the children in foster care have disabilities (Shannon 2011a). Lightfoot and Laliberte found in their research that one-fifth of children with substantiated maltreatment were labeled in records as having a disability (2011). Fifty-six percent of participants indicated that children with developmental disabilities are referred to child welfare services more often than typical children (Rao 2019).

Children with developmental disabilities are more likely to be maltreated than children who do not have developmental disabilities by anywhere from 1.5 to 10 times more likelihood (Shannon 2011a). One study found that children with disabilities are 3.1 times more at risk for neglect, 3.1 times more at risk for sexual abuse, and 3.8 times more at risk for physical abuse and children with severe intellectual disabilities were found to be at the highest risk for maltreatment. (Shannon 2011a). Lio and Park found in their study that 90% of the children adopted from the US public child welfare system had at least one special need (2017).

It was also found that children with a developmental-medical disability condition were less likely by 38% to be returned to their parents than children who did not have a developmental-medical disability and developmental medical problems are associated with longer stays in foster care (Rosenber 2004). It was also found that children with multiple disabilities were significantly more likely to live in an out of home care foster care setting such as a residential home (Simmel 2016). Social workers often have a hard time placing children with disabilities as they often have complex behavioral, education, health, and developmental needs and when a suitable foster home cannot be found a group home or group care facility must be used (Shannong 2011a).

However, the exact numbers for how many children in the child welfare system have development disabilities is unknown. Lightfoot and Laliberte found in 2006 that only 33% of states' child welfare system reported documenting information about specific disabilities of children within their system and in federal legislation Child Abuse Prevention and Treatment Act (CAPTA) there is no requirement for states to collect this information (2011).

On the Washington state Department of Children, Youth, and Families web page for Practices and Procedures, there is a police 45171 for medically fragile children and policy number 6660 which is related to disability insurance benefits for children in out-of-home placements, but no other specific polices about working with children with disabilities. On DCYF's web page for Racial Equity, Diversity, and Inclusion the main focus has been on the disproportionality of race in child welfare which is an important issue that needs to be addressed. However, this has been expanded to include "sexual orientation, gender identity, gender expression and geographic areas." Disability is lacking as a goal for addressing and gathering data on in the department. From an intersectional feminist lens disability is incredibly important

to talk about when also talking about race and gender identity because race and class especially come into play with disability and access to resources. When looking on the DCYF webpage that lists their Case Service Policy, under policy 5780 “Developmentally Disabled Children” there is nothing written. This could be just a glitch on the webpage; however, it is the only policy with nothing written underneath it which suggests that nothing has been written.

The Developmental Disabilities Administration (DDA) has a very specific function and very specific services that they provide (S. Imsland, Personal Communication, November 30th, 2020). For DDA services is that clients have to request services and then be assessed for if they qualify for services which can be an extremely long process that is difficult for families in crisis to navigate (L. Thompson, Personal Communication, December 3 2020). Issues of funding also come up when determining which agencies will be able to access Title IVE funding for services as both agencies cannot access the same money to pay for something twice (Thompson 2020).

There is a lack of focus and value placed on child well-being in the United States, in other countries maltreatment is seen in the context of child well-being whereas in the US there is a focus on child safety (Berrick 2018). Another larger cultural issue is the lack of value people with disabilities have in American society in general. Adults with disabilities are often paid less than minimum wage for doing the same job as an abled person. It is often viewed as a waste of time to adapt or be accessible to a disabled person needs and child welfare is not excluded from this.

One study found that police officers and prosecutors placed a lower priority on cases involving children with intellectual disabilities because they were viewed as unreliable witnesses (Shannon 2011a). Another study found that cases involving children with cerebral palsy were less likely to be seen as warranting further investigation and that there was a difference in the

responses of CPS case workers if the alleged child victim had a disability (Manders 2009).

Children with disabilities are also sometimes viewed by workers as contributing to their own abuse (Manders 2009). This reflects the lack of value as well as ableist ideas about children with developmental disabilities.

In my personal experience, both during my practicum with the department and while working for the Tacoma Public School District, social workers were often ill equipped to work with children with developmental disabilities when it came to interview them. When it came to providing resources and interventions the workers would look for the best possible but often the evidence-based practice service providers it was difficult to make it work for the family as those services are often based on families with neurotypical and non-disabled children.

Policy & Data Collection

For setting up a data collection work with the digital teams who manage FamLink as well as a partnership with the Racial Equity, Diversity and Inclusion team will need to be set up. On DCYF's web page for Racial Equity, Diversity, and Inclusion the main focus has been on the disproportionality of race in child welfare which is an important issue that needs to be addressed. However, this has been expanded to include "sexual orientation, gender identity, gender expression and geographic areas." Disability is lacking as a goal for addressing and gathering data on in the department. From an intersectional feminist lens disability is incredibly important to talk about when also talking about race and gender identity because race and class especially come into play with disability and access to resources.

Once the data collection page has been created and integrated into FamLink, training of current and newly hired workers on how to use it as well as explaining its importance is needed. Training will need to start first with educating the Regional Administrators and Area

Administrators, once they are trained training of unit supervisors can begin. It is important to focus initial training efforts on those who supervise and oversee field workers so that they can properly explain the importance of the form to their workers as well as provide assistance on the ground for navigating what information needs to be collected. The training of workers who are currently hired can be done through the Alliance website and both an online recorded training as well as a webinar training. These trainings would be ideally interactive so that workers can practice looking for and gathering the information that is needed for data tracking. Please see the appendix for the FamLink data collection questions.

A series of emails explaining the new practice and what it means for both the department and workers will also be done. Emails will be sent out with the link to the online training and reminders to workers who have not yet done the training that is required. An email will also be sent to supervisors of workers who have not yet completed the training if it has been 2 months since the training was initiated and workers have still not done it. At DCYF headquarters the data analyst team can share monthly progress in how much data and information is collected so that workers can see how their action of filling out the form for all their cases is helping with understanding demographics and needs of clients and families. Workers are the ones who are doing the bulk of the work gathering information and as such they need to be included in seeing the results of their work and what it means to them. Once workers are trained and the collection of information is steady data analysts and DCYF headquarters can start creating models for statistical analysis in partnership with those involved in the Racial Equity, Diversity, and Inclusion board to see what issues of inequity there might be seen in data as well as once trends are identified either how to mitigate trends of inequity and/or disproportionality and encourage ones that are equitable and reduce disproportionality. It is important to note that because of

intersectionality issues of race, class, gender, and sexuality cannot be excluded from conversations of equity. Data analyst will also need to analyze any relationships between these other areas of identity, oppression, and privilege. Please see the appendix for information about what questions the data analysis need to examine.

Applied Behavioral Analysis Therapy

The second intervention is to a contract with a provider of Applied Behavioral Analysis (ABA) in home therapy services that uses the Essentials for Living Assessment (ELA) to provide services to families involved with DCYF. The data tracking system would be implemented statewide to better understand the relationship of placement, returning home, and supports needed in Washington State child welfare. The ABA in-home therapy contract would be implemented in Region 5(Pierce & Kistap Counties) and assessed for statewide implementation.

DCYF Region 5 administration in partnership with headquarters will begin contacting and sending information to ABA therapy provider agencies in both Pierce and Kitsap counties that they are interested in contracting to provide services to their families that have children with developmental disabilities. Emails and phone calls to connect with agencies in region 5 to discuss and negotiate what the department will be requiring and needing from them. Once contracts have been put in place workers will receive and email announcing the new service and explaining what it is and who the service is targeted towards. Posters about the new service will be put up in every region 5 office and a flyer also explain what the services, who is for, and how to make a referral will be placed on every workers desk for them to have in their cubicle.

The indicators for outcome 2, which is that a contract will be set up with an ABA in-home therapy service providers in Region 5 (Pierce & Kitsap counties) are that after a year of the program starting there will be 20% few children with developmental disabilities in foster care in

Region 5. Again, in order to assess this the data tracking system needs to be in place otherwise there is no way of knowing that there is a reduction in the number of children in foster care with developmental disabilities. The second indicator is that after a year there will be a 20% increase in the number of children with developmental disability returning home in DCYF Region 5. There will also be a collection of the EFL assessment both at the beginning of services for a family and another assessment at the end to document if ABA therapy helps to improve behavior and skills. There will also be a post service survey of the parents asking questions on a scale of 0-4 for how helpful they found it. See appendix for parent post service survey questions.

DCYF will need to communicate clearly with potential ABA therapy providers that they will need to use the EFL assessment if not the whole curriculum and share the analysis with DCYF as well as updates on improvement with the case worker. ABA therapists and DCYF caseworkers should keep in mind that ABA therapy was designed with a white middle-class family dynamic in mind and that is not the majority of DCYF families. ABA therapists will need to be culturally competent in their services and recognize that each family will have unique needs to be met. During the initial assessment process, the DCYF caseworker should be involved as much as possible so that when goals are made the department concerns are also taken into consideration. The department will also need to keep in mind the current controversy around ABA therapy and the potential negative impacts that adults who received ABA have shared. Being mindful that while ABA is evidence based and has research backing up that research often comes from a white, middle class, and neurotypical perspective. The department, ABA providers, and families need to recognize and embrace neurodiversity.

Benefits & Barriers

One of the main benefits of this project would be the creation of a data tracking system. No current system exists in Washington state DCYF which means that knowledge about how frequently children with disabilities are removed from parents, frequency or infrequency of placement disruption, race of children with disabilities in child welfare, how frequently are children with disabilities returned home, and even just the number of children with disabilities who are currently in care. The lack of data means that there is a lack of understanding about the scope of the problem and without knowledge of the exact extent of the disproportionality or trends in the data means that it is difficult to assess for appropriate interventions for children and families. The benefit of including ABA therapy specific contractor would mean that a more targeted intervention for families who have a child with a developmental disability, current EBP programs and interventions are more based around the function of neurotypical children and families.

One of the major barriers to a FamLink Data input system would be making sure all workers are trained how to use it. A CHET worker could be initially assigned to input the data when a case in in the front end but CHET workers only work on cases that come into care in the first 90 days. If information changed or more information was collected after the 90 days a different worker would need to input the information. There is also the issue that CHET workers only collect information for children in foster care and not all child welfare cases involve a child being in foster care. One other issue that could potentially arise is that there have been discussions of retiring FamLink in general and updating to a new agency wide platform. If this is the case then instead of adding this to the existing FamLink the data collection form would be added in the creation of the new platform.

Something else that is important to both discuss and acknowledge is that certain Autism organizations have advertised ABA therapy as a “cure” for autism. This is not true. According to the Cambridge Center for Behavioral Studies and their survey of 45 different independent studies “ABA does not cure all children of autism, ABA has not been compared to other treatments, and Research has not yet identified who benefits most from ABA intervention.” ABA is considered to be an effective and evidence-based behavior intervention and the Cambridge Center does point out as well that all the articles they cite show positive results. However, other studies have shown that ABA has the potential to cause more harm as well as trauma to the individual because it focuses more on making the individual “normal”. It is based on the theories of Skinner and behavioral reinforcement. The importance of how the provider approaches ABA therapy and their methods can make all the difference. It means the department would also need to make sure that the provider is using the methodology they want for ABA. ABA therapy is also more focused on the child which can help to address behavioral problems and possibly teach the parents how to manage their child’s behaviors but it means that there is a gap in working with parents and future services would need to be developed for a parenting program for parents of children with disabilities.

The assessment tool that ABA therapists would use is the Essentials for Living (EFL) assessment instrument. This assessment is focused more broadly on life skills of developmentally delayed children and adults. There are 8 essential skills this is based around: making requests, waiting, accepting removals, completing brief previously acquired tasks, accepting ‘no’, following directions, completing daily living skills, tolerating situations. EFL also measures small increments of progress to indicate quality of life improvement. However, not all providers are trained in EFL and it could be a potential challenge to locate a provider who

does use it. Because this particular variation of ABA assessment and therapy can be done with all ages there is a potential to adapt this program in the future to work with parents who have developmental delays on parenting skills.

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Appendix

Collection Methods

Data Collection Questions in FamLink:

- Official diagnosis(es) -separate boxes for each diagnosis and not a list
- IEP?
- Behavioral needs?
- Medical needs? (i.e. medications, colostomy, diabetic devices)
- Dietary needs? (i.e. drink thickener, feeding tube, solid or nonsolid food)
- Accessibility needs? (i.e. mobility aids, hearing devices, speech devices, red cane)
- Are they currently receiving DDA services?

Questions for Data Analysis

- What is the rate of return home for children with disabilities?
- How frequent is placement disruption for children with disabilities?
- How frequent are children with disabilities removed from their home?
- How many children of color in foster care also have a disability?
- Is there a relationship between gender and disability in foster care?

- What evidence-based practice services are families who have a child with disabilities receiving?
- How frequently are parents of children with disabilities having their parental rights terminated?
- What are the statistical rates of abuse and neglect for children with disabilities?

Parent Post Service Survey

- was the service helpful?
0 -not helpful 1-slightly helpful 2- helpful 3- very helpful
- Did the therapist address the issues?
0 -not helpful 1-slightly helpful 2- helpful 3- very helpful
- Did you feel like the therapist listened to your needs?
0 -not helpful 1-slightly helpful 2- helpful 3- very helpful
- Do you think there is an improvement from before you started services to now?
0 -not helpful 1-slightly helpful 2- helpful 3- very helpful

Problem Statement Analysis:

Societal value that explains why this problem exists:	Lack of value/emphasis placed on child well-being in the US.
The cause below is caused by this:	Lack of training on how best to serve children with developmental disabilities.
The cause below is caused by this:	Social workers are overwhelmed by high caseloads.
Problem statement below is cause by this:	Social workers lack time and knowledge to do best practice for children with developmental disabilities.

PROBLEM STATEMENT	Children with developmental disabilities have poorer outcomes both while in the child welfare system and upon leaving the system.
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The problem leads to this consequence:	Children with developmental disabilities in child welfare often remain longer in care.
The consequence above leads to this consequence	More of social workers case load and time needed for children with developmental disabilities placing even more of a burden on them.
The consequence above leads to this consequence	Higher cost to the system and funding to care for these children while they are in care.
Which costs society:	More money is spent on the health care, mental health needs, and finding suitable care givers for these children.

Force Field Analysis:

RESTRAINING FORCES (obstacles or barriers to achieving the goal) Identify 5 policy, attitude, program, resource or other restraining forces	
1	Lack of time in case workers
2	Lack of community resources for developmental disabilities
3	Needing more collaboration with community resources that specialize in developmental disabilities.
4	Little to no policy/procedure on working with children who have developmental disabilities in WA Department of Children Youth and Families
5	Ableist attitudes among case workers and foster parents.

GOAL STATEMENT (what you hope is accomplished):
Improved outcomes for children with developmental disabilities would look like shorter times of remaining in care, higher statistical likelihood of returning to birth parents, and more stable placement.

DRIVING FORCES (things that support the goal) Identify 5 policy, attitude, program, resource or other supporting forces	
1	Case workers being more knowledgeable about developmental disabilities
2	Interagency collaboration has been shared by social workers as important for case success (especially need to collaborate with disability service agencies)
3	Having a disabilities specialist to assist with cases involving developmental disabilities.
4	Adapting CPS system capacity to meet the needs of families that have developmental disabilities.
5	Provide supports specific to foster parents who are caring for children with developmental disabilities.

Logic Model

Logic Model**Needs Statement:**

Children with developmental disabilities when involved in the child welfare system are less likely to be returned to their birth parents, spend more time in care than neurotypical peers, and experience frequent placement disruption.

Theory & Key Assumptions	Resources	Activities (Process objectives)	Outputs * (Outcome/Summative Objectives)	Outcomes (Short Term Goals)	Outcome Indicators* (Outcome/Summative Objectives)	Long Term Goal
Anti-Oppressive Social Work Framework Intersectionality	*FamLink *Racial Equity, Diversity, & Inclusion (DCYF initiative) *DDA *ABA Therapy Providers	*Develop method for collecting and tracking data on disability in FamLink. Specifically, information about what their disability is, educational needs, health needs, mobility, and diagnosis. To be filled out by the CHET worker in the first 90 days and if needed filled out/updated by the CFWS workers. *Find a provider of ABA in home therapy services that is willing to contract with the state to provide services to families involved with DCYF. Document feedback from families about how this is working because ABA is not technically an	* A form created in Famlink to track and collect data about children with developmental disabilities. This data can be analyzed to track trends in needs, inequity, and data that might indicated a need to revise the SLAs with DDA. *A contract would be set up with ABA providers in DCYF Region 5(Pierce and Kitsap Counties). Information on effectiveness for families will be collected in DCYF Region 5(Pierce and Kitsap Counties) to see if it is something worth implementing statewide.	Outcome 1: Creating data tracking system for DCYF internal database FamLink. Outcome 2: Contract set up with ABA in home therapy service providers in Pierce County.	Indicator 1a. After 6 months an accrual of data is noticeable. Indicator 1b. After 1 year enough data is collected to be able to do statistical analysis. Indicator 2a. After a year 20 % fewer children with DD will be in foster care in DCYF Region 5(Pierce and Kitsap Counties). Indicator 2b. After a year there will be a 20% increase in children with DD returning home in DCYF Region 5(Pierce and Kitsap Counties).	The ultimate goal would be to improved outcomes for children with developmental disabilities and to create equity for children with developmental disabilities in the child welfare system.

		EBP but because it is more focused on autism it is more successful in home than other EBP providers.				
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Data Collection Sheet:

Outcomes & Criteria	Tools	Data Collection Process	Data Collection Method	Validity
<p>Outcome 1: Creating data tracking system for DCYF internal database FamLink. *Indicator A: After 6 months an accrual of data is noticeable. Criteria to achieve indicator A: There is enough data collected by CHET and CFWS workers after 6 months to start to identify trends in the data. *Indicator B: After 1 year, enough data is collected to be able to do statistical analysis. Criteria to achieve indicator B: Statistical analysis of the data begins to show areas for need, improvement, or inequity.</p> <p>Outcome 2: Contract set up with ABA in home therapy service providers in Pierce County. *Indicator A: After a year 20 % fewer children with DD will be in foster care in DCYF Region 5(Pierce and Kitsap Counties). Criteria to achieve indicator A: All families and children who qualify and are involved with DCYF will be referred for services. *Indicator B: After a year there will be a 20% increase in children with DD returning home in DCYF Region 5(Pierce and Kitsap Counties).</p>	<p>Outcome 1: (List tool and why selected) *Famlink-this is the DCYF internal data tracking system for anything that is involved in a case this includes information such as addresses, demographics, case notes, police reports, and other relevant information to a case.</p> <p>Outcome 2: (List tool and why selected) *A pre-service assessment of family's needs *post-service assessment *post-service survey of family about the services they received *examine the numbers of children with DD in care and those returned home.</p>	<p>Who collects the Data? Outcome 1: Famlink data collected by CHET workers. If necessary data can be collected by other workers (Investigations, FAR, CFWS, or Adoptions). Outcome 2: The assessments and surveys data will be collected by the ABA service provider and shared with both the service provider and DCYF.</p> <p>When-At what points in time is the data collected? Outcome 1: When a child comes into care or if a worker & their supervisor identify the data as relevant to the case. Outcome 2:</p>	<p>Do you gather data on ALL Clients? YES or NO</p> <p>If NO, what SAMPLE STRATEGY do you use? (Random, Stratified, etc.)</p> <p>What is your RATIONALE for using the identified strategy?</p>	<p>FamLink Data: The data collected will be based on medical diagnosis, school information (IEP and learning assessment), and use the DDA's assessment tool. Applied Behavioral Analysis Therapy: Several studies have shown significant improvement in participants who have received ABA. Most commonly used with autism spectrum disorder but can be used with other diagnosis as well. Survey: Will use a scale of 0-4 and asking questions such as: was the service helpful? Did the therapist address the issues? Did you feel like the therapist listened to your needs? Do you think there is an improvement from before you started services to now? Assessments: The Essentials For Living(ELF) assessment tool that is used by some ABA providers will be use.</p> <p style="text-align: center;">Reliability</p> <p>Identify step(s) to ensure (List the most important - at least one step for each tool) FamLink: Data collected for all children with DD who are involved with DCYF. Assessments & Surveys: Assessment used pre and post service for every case that involves ABA therapy.</p>

<p>Criteria to achieve indicator B: Pre-referral to ABA services data and information will be collected and post-return home and after services survey of families will be collected.</p>	<p>(all survey and assessment tools will allow examination of how ABA therapy works for families as well as how families see the service working for them.</p>	<p>*The pre-service and assessments will be done at the beginning or before services begin. *The post-service surveys and assessments will be done when services come to an end.</p>		<p>Survey will always be given to parents after ABA services.</p>
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