

Family Engagement in the Individualized Family Support Plan Process (IFSP)

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Background

- Family Centered Early Supports and Services (FCESS) enhances families and caregivers in their ability to care for children (from birth up to age 3) with delays and disabilities.
- Together with families, FCESS develops an Individualized Family Support Plan (IFSP):
- Plan for service delivery
- Assistance with coordination of services
- Identification of and coaching for use of strategies to support goal attainment and growth within the child's natural environment
- New Hampshire Family Voices (NHFV) and the Bureau for Family Centered Services continued research from 2019 to evaluate levels of family engagement within the IFSP process one year later.
- NH FCESS, NHFV, and the **LEND** program's missions are aligned in their collaborative commitment to improve family engagement and systems of care for children and families with special healthcare needs and disabilities.

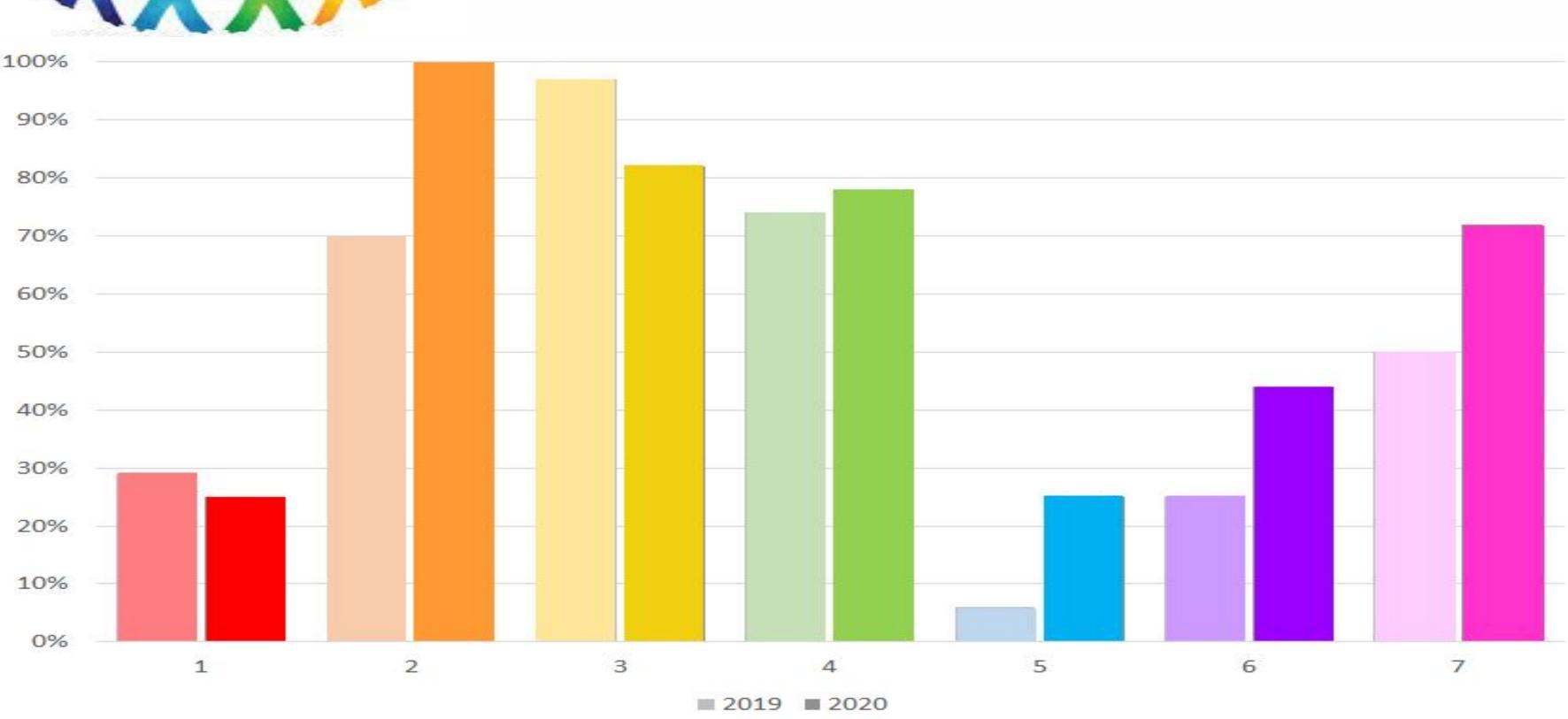
Description of Activities

- Trainees developed a survey for providers and families to support and augment feedback consistent with the original data collection tool used (as developed in 2019).
- Trainees coordinated communication with 15 programs to set up in-person observations of annual IFSP meetings.
- The majority of meetings included the child's re-evaluation.
- Trainees completed 9 observations, were unable to schedule 2, and were forced to cancel 4 observations due to the COVID-19 pandemic.
- Trainees applied interdisciplinary perspectives throughout the process to compare findings and track trends in observations.

*Comparison of all data between the two years of observations could be influenced by changes in the providers observed, in addition to or in place of any changes in emphasis programs have implemented over the past year



Family Engagement: 2019 vs. 2020





- 1: Interactive discussion of family
- role as team member (Q1, Q2) 2: Explanation of any jargon used/avoidance of jargon use (Q9)
- 3: Providers check-in regularly and answer questions effectively (Q3, Q5,
- 4: Family members as the driver of the goal-writing process (Q11, Q12, Q13, Q14)
- 5: Active inclusion of family members in attendance throughout all discussion (Q7, Q8)
- 6: Active involvement of family members in determining service provision (Q15)
- 7: Discussion of outside resources (Q16)

Key Research Findings

5



Interactive discussion of family role as team member

Families are compliant as team members. The potential for increased family engagement is not being developed through of the family's role as a team member by the provider. with building an engaged team of people for the IFSP team.

Providers check-in regularly and answer questions effectively

Providers answered questions effectively when asked yet are not

moving beyond the parent-interview stage of this. We observed this

same interview style throughout our observations. Rapport and

trust should already be established, and the growth of the team

should be moving in the direction of encouraging family advocacy.

Explanation of any jargon used/avoidance of jargon use

Jargon usage has decreased from last year, yet thorough explanations of the IFSP process and key terms used including eligibility requirements, defining and explaining developmental areas and milestones, and explaining transition processes need

Family members as the driver of goal-writing process

Goals are suggested and/or written by providers and agreed upon by

families with little to no input or change. Providers often ask families

for the focus, but the language is always translated by the providers.

Families are asked to sign documents only seeing or hearing rough

drafts of goals.



Active involvement of family in determining service provision

Most often, this was not a discussion. Providers reported the service provisions and waited for acceptance from the family. It was observed that the majority of families did not seem aware that they could request something different.



Discussion of outside resources

Active inclusion of family in attendance throughout all discussion

Meetings were attended by only mothers in 7 out of 9 cases. When

rainees observed additional attendees, providers worked to engage

all participants and asked about the goals and concerns of missing

parents. Meeting length has improved and was closely attended to

by providers in most cases in respect of the families.

Connecting services and resources beyond FCESS is very important. This was discussed in the majority of our observed meetings, an improvement from last year, yet it is our observation that there needs to be more concrete support and education surrounding this nformation. This should/could be done as part of case management services with connections being facilitated between families and suggested supports.



Next Steps

- Trainees will draft a summary report of our findings with recommendations for future action.
- Development of an action plan including ideas for more consistent use of tools previously created as well as strategies for building the engagement and advocacy of families, and the leadership and team building skills of providers.
- Strategies include, but are not limited to: trainings, mentor programs, etc.

Observation Tool/Surveys

N	/A YES	NO	Observable concept	
1.			The role of the family/caregiver as a "team member" was explained	
2.			There was Interactive discussion about the family/caregiver role	
3.			Did check-ins occur with the family/caregiver throughout the meeting to support their participation	
4.			The family/caregiver was offered a break?	
5.			The family's/caregiver's questions were answered?	
6.	Ž.		Were decisions made or asked to be made based on time limitations?	
7.			Did staff notice if a family/caregiver got 'quieter' or their participation decreased?	
8.			Did the staff make an effort to engage the family/caregiver who was not actively participating?	
9.	7		Was jargon/acronyms used, without explanation?	
10.			Was there conversation about the child's "everyday" activities?	
11.			Was the family/caregiver asked Questions such as:	
			"What do you think your child needs?"	
	_	-	"What would you like your child to do? Short term and long term"?	
12.			Was there an explanation of the approach that would be used for home visits – that providers would offer suggestions and then the providers and the family/caregiver would discuss ways that the approaches/activities could be done with the child day to day?	
13.			Was the family/caregiver given the opportunity to decide what areas/needs they worlike to approach first?	
14.			Were the family/caregiver involved in the development of goals and activities?	
15.			Were the family/caregivers involved in the decision making about which provider(s) would be working with them?	
16.			Was there a conversation about the resources that might interest the family/caregiv (both from Part C and other providers)?	

	N/A	YES	NO	Observable concept	
1.	0	9	0	Do you feel you included the family as a member of the team?	
2.	2	6	1	Was there interactive discussion about the family's role as a member of the team?	
3.	0	9	0	Did you support the family's participation in the process?	
4.	0	3	6	Did you offer the family a break?	
5.	2	7	0	Did you feel the family's questions were adequately answered?	
6.	2	1	6	Were decisions made or asked to be made based on time limitations?	
7.	0	2	7	Did you notice if the family/caregiver got 'quiet' or their participation decreased??	
8.	5	3	1	Did you make an effort to engage the family/caregiver who was n actively participating?	
9.	3	5	1	Did you explain jargon/acronyms or did families ask for clarification?	
10.	0	9	0	Did you ask about the child's "everyday" activities?	
11.	0	9	0	Was the family/caregiver asked Questions such as: "What do you think your child needs?" "What would you like your child to do? Short term and long term"	
12.	4	4	1	Was there an explanation of the approach that would be used for home visits – that providers would offer suggestions and then the providers and the family/caregiver would discuss ways that the approaches/activities could be done with the child day to day?	
13.	2	7	0	Was the family/caregiver given the opportunity to decide what areas/needs they would like to approach first?	
14.	2	7	0	Were the family/caregivers involved in the development of goals and activities?	
15.	2	5	2	Were the family/caregivers involved in the decision making about which provider(s) would be working with them?	
16.	1	7	1	Was there a conversation about the resources that might interest the family/caregiver (both from Part C and other providers)?	

	N/A	YES	NO	Observable concept
1.	0	9	0	Do you feel you were included as a member of the team?
2.	0	9	0	Was there interactive discussion about your role as a member of the team?
3.	0	9	0	Do you feel that your participation in the process was supported
4.	5	2	2	Were you offered a break?
5.	0	9	0	Were your questions answered?
6.	0	9	0	Did you feel you were given adequate time to make decisions?
7.	0	9	0	Was your participation elicited and supported?
8.	0	9	0	Did you feel engaged by the team throughout the meeting?
9.	0	8	1	Were there jargon/acronyms used that you did not understand?
10.	0	9	0	Were you asked about your child's "everyday" activities?
11.	0	9	0	Were you asked Questions such as: "What do you think your child needs?" "What would you like your child to do? Short term and long term"
12.	1	8	0	Was there enough information given about the approach that would be used for home visits? Do you understand how this will work moving forward?
13.	1	8	0	Were you given the opportunity to decide what areas/needs you would like to approach first with your child?
14.	1	8	0	Were you involved in the development of goals and activities?
15.	1	8	0	Were you involved in the decision making about which provider(would be working with your family?
16.	0	9	0	Was there a conversation about additional resources that might help you?

Conclusions

- Increased family engagement in annual meetings as compared to evaluation/IFSP meeting.
- Growth is in specific silos, not in the development of the family as a full-fledged team member.
- Providers are more consistently reviewing the process or explaining the steps as they go through them.
- Families are compliant team members, accepting what they are told and given; not asking questions or seeking more information and not being expected to engage and advocate.
- Information is shared as reporting to one another through answering survey questions and IFSP line items, not through discussing actions and outcomes as they relate to progress and work toward goals.

Institute on Disability/UCED





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