What Do Youth and Parents/Guardians Think About Information Sharing?

Formative Focus Group Report

December 2011

Acknowledgements

The Center for Network Development and JSI Research & Training Institute, Inc. (JSI) wish to thank all of the youth and parents/guardians who participated in these focus groups and openly voiced their needs, concerns, and ideas regarding cross-agency information sharing. We pledge to use this information wisely and to improve child and youth information sharing practices within the State of Colorado.

"To me, it's comforting that people actually want to hear what we have to say when we're the ones living it."

Please note: When speaking of "information sharing," we are referring to the process and data about youth and families that multiple agencies collect, *share*, and use to improve youth and family outcomes.

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Background

Office of Juvenile Justice and Delinquency Prevention

The Office of Juvenile Justice and Delinquency Prevention (OJJDP) provides national leadership, coordination, and resources to prevent and respond to juvenile delinquency and victimization. OJJDP supports states and communities in their efforts to develop and implement effective and coordinated prevention and intervention programs, and to support the juvenile justice system so that it protects public safety, provides tailored treatment and rehabilitative services, and holds offenders accountable.

The National Juvenile Information Sharing Initiative

State and local jurisdictions across the United States are working to improve information sharing among key agencies that are responsible for community safety and the health and well-being of at-risk children and youth. These agencies often have difficulty receiving timely and reliable information needed to conduct assessments and determine appropriate supervision and services. Juvenile information sharing (JIS) benefits have been cited to:

- Enable decision makers to electronically access and exchange critical information at key decision points.

- Facilitate more efficient access to data and information from multiple locations.

- Improve data quality.

- Eliminate redundant data collection and entry.[1]

JIS requires new processes and procedures for electronic information sharing and requires developing and applying new knowledge and skills.

To this end, the OJJDP funded the National Juvenile Information Sharing Initiative (NJISI) administered by the Center for Network Development (CND) to work with juvenile justice, youth services, and community and state leaders to effectively coordinate multiple services and foster informed decision making regarding juveniles, whether in the justice, education, health, or welfare contexts. In this endeavor, CND serves a wide array of agencies and professionals who are responsible for the health, safety, and well-being of at-risk youth, juvenile offenders, and their families. These audiences include courts, schools, behavioral health agencies, prosecutors, public defenders, child welfare, family advocacy organizations, higher education, detention, corrections, diversion, probation, employment, community, and prevention programs.

CND has assisted more than 680 juvenile justice and other youth service professionals in addressing the challenges and barriers to JIS through multi-level instructional training and technical assistance.

> "The sharing of essential information between multiple agencies and across systems through structured procedures to improve outcomes for youth and families"[2] and to protect communities is key to the success of youth and families today.

CND continually works to address the significant challenges to JIS by developing protocols and standards for juvenile information sharing through the National JIS Initiative and the lessons learned through its pilot sites. Missing in this effort has been the voices of youth and parents/guardians. Thus, to inform this work, JSI for CND coordinated and conducted focus groups in 2010 and 2011 in an effort to gather youth and parent/guardian perspectives, perceptions, attitudes, and needs concerning the sharing of data by Colorado-based agencies.

Overview of Focus Group Process

The Family/Youth Involvement Subcommittee of the Colorado Children and Youth Information Sharing Collaborative (CCYIS), one of the pilot sites of the NJISI, was charged with planning incorporation of youth and family perspectives. Subcommittee members, with the help of JSI, developed the recruitment strategy, facilitation protocol, and the semi-structured focus group interview guides. Ten discussion groups (5 youth and 5 adult) were held in the early summers of 2010 and 2011. During analysis of the 2010 data, it became apparent that the groups were confused as to the intent of the discussion, which was cross-agency information sharing. This confusion caused discussions to center on the sharing of personal information with agencies. The 2011 process provided more explanation and examples of the meaning of agency information sharing, which clarified the original intent for these participants. For this report, both sets of data were analyzed.

Focus Group Recruitment

Members of CCYIS representing the Colorado Department of Human Services, county youth diversion and probation programs, and a family involvement group, which were geographically dispersed throughout Colorado, identified potential group participants and scheduled the meetings in community settings. Each group had a note taker and a discussion group facilitator. In addition, all groups were audio recorded.

Consent and youth assent signatures were obtained. Each group began with an explanation of the purpose of the discussion, definitions and examples of the terms used, an explanation of the ground rules, and then simple first-person introductions. Each participant completed a short anonymous demographic survey. An incentive of a $10 dollar gift card was given for participation.

A semi-structured focus group interview tool guided discussion so that information could be gathered concerning:

- Client perspectives on the information requested at intake into the "system" from the multiple intake points (i.e., juvenile justice, behavioral health, human services, etc.), what it was used for, where they thought it went, and if they knew exactly where it went.

- Any explanations clients remembered given on how information would be used and/or shared, and their rights in having their information shared.

- Recollections and understanding of signing releases or consents.

- Experiences of giving information and comfort level in this disclosure.

Qualitative Data Analysis

Audio recordings were transcribed verbatim to anonymous text data. JSI staff then downloaded the text data into ATLAS.ti© Version WIN 5.0 Qualitative Data Analysis Software. A combined template and editing organizing style allowing emerging themes were used.[3] First, general broad codes were developed related to each semi-structured question. Then, an editing approach derived from grounded qualitative analysis theory was applied, which allowed for separation of preconceptions and identified emerging themes. The themes and subcategories were organized into an overall

Table 1: Focus Group Demographics		
Youth (n=52)	**N**	**%**
Age		
12 – 14	6	11.5%
15 – 17	28	53.8%
18 – 20	14	26.9%
21 Years & Older	2	3.8%
No Response	2	3.8%
Gender		
Male	31	59.6%
Female	21	40.4%
Race/Ethnicity		
American Indian/Alaska Native	1	1.9%
Asian	2	3.8%
African American	2	3.8%
Hispanic/Latino	12	23.1%
Non-Hispanic White	29	55.8%
Mix Race	4	7.7%
No Response	2	3.8%
Parent/Guardian (n=27)	**N**	**%**
Age		
21 – 29	4	14.8%
30 – 39	5	18.5%
40 – 49	7	25.9%
50 Years & Older	11	40.7%
Gender		
Male	4	14.8%
Female	23	85.2%
Race/Ethnicity		
American Indian/Alaska Native	1	3.7%
Asian	1	3.7%
African American	1	3.7%
Hispanic/Latino	5	18.5%
Non-Hispanic White	19	70.4%
Employment		
Full-time	11	40.7%
Part-time	1	3.7%
Not Employed	12	44.4%
Retired	3	11.1%
Number in Household		
1 – 3	9	33.3%
4 – 6	13	48.1%
7 – 9	5	18.5%
Marital Status		
Single/Never Married	5	18.5%
Married	16	59.3%
Separated	2	7.4%
Divorced	4	14.8%
Total Number of Children		
1 – 2	8	29.6%
3 – 4	9	33.3%
5 – 6	7	25.9%
7 – 8	3	11.1%
Household Income		
Under $29,000	8	29.6%
$21,000 – $29,999	3	11.1%
$30,000 – $39,999	4	14.8%
$40,000 – $49,999	2	7.4%
$50,000 – $59,999	1	3.7%
$60,000 – $74,999	4	14.8%
Over $75,000	3	11.1%
No Response	2	7.4%

framework to describe the conceptions, issues, and complexities experienced by youth and parents/guardians in giving information and having agencies share this information.

A total of 79 persons (52 youth and 27 adults) participated in the focus groups. A summary of the participants' demographic information is provided in Table 1, *left*.

A slight majority of the youth were non-Hispanic, white males between the ages of 15 and 17. The vast majority of the adults were female and non-Hispanic white. Approximately 37% reported having five or more children at home. All participants indicated that they spoke English at home.

Tables 2 and 3, *below*, show responses from both participant youth and parents/guardians regarding multi-system involvement.

Table 2: Youth Responses		
	N	**%**
Child Welfare/Social Services	7	13.5%
Juvenile Justice	34	65.3%
Mental Health	7	13.5%
Education	24	46.1%
Substance Abuse Treatment	13	25.0%
No Response	7	13.5%

Table 3: Adult Responses		
	N	**%**
Child Welfare/Social Services	15	55.6%
Juvenile Justice	17	62.9%
Mental Health	17	62.9%
Education	14	51.9%
Developmental Disabilities	11	40.7%
Substance Abuse Treatment	6	22.2%
Other	1	3.7%

Focus Group Discussion Results

Themes and subthemes are presented below with illustrative quotes from youth and adult participants.

Overall Perspectives

Both parents/guardians and youth assumed that any information that they disclosed would be shared.

Parents'/Guardians' Overall Experiences

Information Needed to Obtain Help

Overall, the vast majority of the adult participants were very open to disclosure and accepting of agency sharing of information as long as they felt trust and partnership in the process, a caring atmosphere, accuracy in the information, and an expected benefit to their youth and families. They felt that agencies needed the information to manage their child. In some cases, the parents/guardians felt desperate in seeking help, even claiming themselves neglectful in order to obtain it.

One parent said, *"… that's what it comes down to is when you get the best care … when you have been completely open and honest and not afraid that something's going to happen to you … And, yes, you know, it was lengthy but I found the intake valuable because I wanted them to have the information so they can come up with some sort of a plan to help our son."*

Life Context and Sensitivity of Information

In addressing the concerns and needs of these families, parents/guardians felt that an understanding of their lives and situations was extremely important.

"But you know, a year ago we were scared sh--less. We didn't know what to expect and nobody told us. We just kind of went through and figured it out on our own and made choices that were best for our family. I was always thinking – who are they, what if I say something wrong."

A male parent noted, *"When you're first entering the juvenile justice system, it's – it's a scary system to be in. We feel very often [that] we're walking alone."*

Families are often confused, scared, and do not know the system or what is the "right thing to do." Most participants felt alienated from agency staff whom they felt did not understand their lives or circumstances.

As one gentleman suggested, agency staff should see the patients' environment to better understand the context of the situation. Increased understanding and respect might alleviate client anxiety and feelings of judgment. *"You know? This is about our life; this is what we go through every day."*

As one woman explained, *"You need to know that we feel like we're being judged … you have to get to know us and our lives, you really do and you have to let us know who you are."*

Timing

Requesting information is usually done in a time of crisis. During the crisis, families are in shock, dealing with unfamiliar systems, and afraid. Gathering information at this time can lead to inaccuracy due to the confusion and mental states of the affected parties.

Mistrust

While willing to share information that will help their families, participants noted fear at doing so. They do not trust that the information they are providing will not be used against the youth or family. Some parents/guardians state that they only share information that they feel the agent really needs to know. Two agencies with whom parents/guardians were most guarded are the police and the Department of Human Services (social services).

One woman commented that the police: *"Rush to judgment … I learned to be guarded, not tell the truth of what happened because they have a preconception of what your child did and is."*

Of great concern for the families is whether information will be used, shared, or manipulated to take children from their homes. More than one participant shared a personal experience in which she felt her child had been unnecessarily taken from her home due to agency misinterpretation.

Frustration with Duplication

Families involved in multiple systems are extremely frustrated with the intake processes and disposition requirements of each individual agency with which they are involved. Each agency is perceived by the participants as collecting similar information, which is very time-consuming overall.

Youth Overall Experience

Learned Test-Taking Behavior

Youth explained that sometimes answering questions can happen with multiple agencies and people in one day. To relieve anxiety and boredom, some indicated that they developed "games" when answering questions, such as answering in patterns. Others provide the answers that they learned facilitate completion of the process. If youth provide information in this manner, the data are invalid and results become inappropriate for decision-making.

As one youth stated: *"I don't tell the truth. I just try to get done with it … there's a longer road to certain questions. And [with] other ones you could just stop right there."*

Another youth described the consequence of taking the same test multiple times and giving different answers. *"They will bring it up in court and make it a part of your case. I think it messes you over because you answered that one different."*

Even some parents/guardians, especially those with youth who have mental health and/or behavioral problems, expressed frustration with the number of assessments that are repeated unnecessarily.

Lengthy Intake Affects Disclosure

The lengthy and duplicative intake process frustrates youth. In response, they have learned only to give what they perceive as short and necessary information to **get through and out**. To do this, they give information that they perceive the **agent wants to hear**. They also expressed that they did not see the need for a lot of questions asked them, such as questions centered on sexual health and behavioral health histories. Explanations were lacking as to the "why" of some assessments. However, some youth did mention an understanding that certain information is useful to keep youth safe from suicidal ideation or violence.

Reasons Why Youth May Not Disclose

Participant youth were afraid of disclosing any abuse within the family for fear of getting the family in trouble and/or causing a breakup of the family unit.

One youth explained: *"I won't tell anyone if I have ever seen somebody get hit in the family, like [an] abusive relationship or something like that. It ain't none of their business. Then they're going to start coming into your family life."*

In addition, youth discussed how they avoid providing information that might get them in more trouble, lead to labeling, or lead to more services/programming.

A youth mentioned in discussing more programming: *"Like you tell them you are depressed, you're sad … then you go to court and they say she's severely depressed … so they lock you up and put you in an insane … a crazy house or something. Or they tell you, 'I think you need to go to these certain classes or therapy' … Like you are already in three classes, why six more? Like dang!"*

Perceived Issues for Youth and Family

The Stress of a Long Intake Process

Parents/guardians and youth note that the long process of data gathering adds anxiety to an already stressful time. The need to tell and retell the same story adds to the frustration.

One youth complained: *"[The process] takes too long. The first three-hour test, then the 45-minute test, and then the test that you have to stand up in front of the computer because they can't give you a chair … after the first 20 questions, the next ones are exactly the same but just changed around. I think our stuff is just like to get in and get it over with."*

Accuracy of Information

Many adults and youth were worried about the accuracy of information that was exchanged, which can result in labeling of the youth and families.

Two parents who also serve as advocates stated:
Male: *"We've had kids come to us that they've [agency staff] said were sexual perps, they've done this, they've done that. And it was so far from the truth …"*
Female: *"And it's scary because those kids are labeled then."*
Male: *"Once one person has them moved because of this or that, it's in that file and it goes with them everywhere. And you have to really be careful what*

you say because that goes with them the rest of their life. It's not the availability of the information."
Female: "It's the accuracy."
Male: "Yeah, and it's how they interpret that information."

One youth stated: "Some of the information is inaccurate, however, and then we are judged and labeled with it."

Interpretation of Information

Both parents/guardians and youth expressed concern over misinterpretation of information/data. Correct interpretation is very difficult, yet important, and is complicated and hindered by inaccurate accounts of events.

A youth gave an example of misinterpretation of information that damaged a youth's experience:
"I can't even think of her name but basically what she said is that she said something about a bird, caught a bird … and it got interpreted that she likes to flip people the bird. And it had nothing to do with that. And that information was in her file through all these years in foster care and people wouldn't take her in because of it."

Number of Staff Handling Information and Staff Turnover

Several adult groups discussed their concern that too many people were involved in the process and that facts were skewed as a result. One participant compared this to the children's information sharing game "telephone." High staff turnover was noted to exacerbate the problem.

Privacy in Data Collection

Both parents/guardians and youth agree that disclosures of information should be conducted privately. In particular, parents/guardians of youth who had mental health or behavioral problems worried that information they shared would be passed to their children and disrupt already strained relationships or even lead to violence. Thus, they did not feel like they could be entirely honest and open with their children or agency staff.

One man described his experience as: "In the initial intake, I was extremely uncomfortable. They chose, for some odd reason, to hold that intake with my child right there with me. If the shoes were on the other foot and we were discussing me and my issues, I would be very, very uncomfortable in that circumstance. So the parent, in my mind, is put in a very tough position

of having to be very straightforward but yet saying things that are quite candidly hurtful to the youngster they're trying to help. And so I found that to be a very grueling thing to go through and very hard to deal with as you're trying to deal with what's best for this child. That would be really something I'd like to see changed because I think it's extremely hard on the child and hard on the parents as well."

Youth are also uncomfortable disclosing some information when parents/guardians are present; because of this discomfort, they may be less likely to tell the truth.

Youth and Family Experiences in Consent/ Authorization for Information Sharing

The process for consent of information sharing itself should be private, well-explained, and authorized by all involved. The majority of the focus groups participants neither remembered the process of consent/authorization nor being asked to consent or authorize. However, they do remember forms being placed in their hands and requests for signatures. Those that did remember it as more of a process were clear that this occurred in the health or behavioral health arena where actual treatment would follow.

The most common participant recollection is of a stack of forms/papers put in front of him/her to sign without explanation, usually in a hurried moment. This result does not necessarily mean that a complete process (which included explanation for non-coercive decision-making) did not happen, just that the participants did not remember.

They did not remember being told why the information was needed, or where it would go. When asked if they had been provided any explanation of rights to privacy and confidentiality of their information, almost all participants said no.

As one youth explained, "They just told me you better sign everything."

Of the youth that did read the form(s) prior to signing, it is important to note that the majority did not feel that they had a choice in signing; rather, they signed because they perceived negative consequences if they did not sign (such as not getting services or looking bad to the courts.) They also stated that they signed to 'hurry the processing'.

How to Get "Good" Information

Have a Warm and Welcoming Attitude and Atmosphere and Be Considerate of Life Context

Agency intakes are usually done in sterile office environments using formal and direct questioning, which are not very conducive to relationship building. This way of seeking information hinders disclosure.

Some participants suggested an atmosphere of relaxation and informality may be helpful in appearing less intimidating and more understanding of their lives.

Use Caring, Nonjudgmental and Non-punitive Attitude

The need for a sense of a caring, nonjudgmental, and non-punitive attitude from staff to improve disclosure was a salient theme of the focus groups. One participant expanded on this idea, saying that only "people who listen and work well with [people get the real story]."

Another participant noted: *"A lot of it depends on the person who is trying to get the information. There are certain people that I will not share anything with about my thoughts and my life. If they have an attitude and I know that in the long run that there could be harm, I get protective."*

Families feel that they are just a "number" – another case that is hurried through the system.

Adequately Inform of Agency Process

Agency staff who can take time with clients and adequately inform them about the processes will receive more cooperation. Youth and adults who seemed more hesitant to provide accurate information also seemed to not fully understand the intake process.

Partner with Youth and Families

Many participants wanted to feel like they are working in partnership with the agencies.

One gentleman described his sense of a successful partnership as a feeling that *"you were all in it together."*

Some believed that legal requirements could prevent a partner-like approach between agency staff and parents/guardians, especially for those involved with human or social services.

Youth and parents/guardians who were open in their disclosure of information saw benefits in sharing. Disclosure was facilitated when the clients knew that what they shared would ultimately provide more effective and efficient services for the youth and their families. However, if they do not see that sharing the information will make a positive difference, they are less likely to share additional information or seek help in future situations.

Suggestions for JIS

Both the adult and youth participants were asked for suggestions to improve information sharing. Suggestions can be found or inferred in the preceding results; however, the following suggestions deserve special highlight:

1. Ask for Critical and Relevant Information

Families are asked for a lot of personal information from many different agencies.

"[It] kind of feels like half the state wants to know your business," noted one participant.

Times of crisis are overwhelming for clients; asking them to share information that they think is the most important respects clients' experiences and reduces time spent on unnecessary details.

One woman suggested: *"For the basic information and what other information that [agencies] feel is critical, [the gathering process] should be led by the parents. It could be a little bit guided by the person that's asking but I think it should be understood, too, that the parents should feel comfortable to give important information, relevant information to the situation, things like, you know, mental health behaviors, mental health histories if it's not already documented."*

The youth-defined list of critical and relevant information to be shared was short and included demographics, emergency contact, and information for safety such as suicide ideation.

2. Assure Security of Information

Parents/guardians are fearful of disclosing something that could be harmful to their families. This issue was most important for participants who were or could be involved with child protective services.

One woman stated: *"… what you say is not going to be used against you. You know, like my fear was, okay, well, I tell them about the fact that my son wasn't with me for seven or eight years, they're going to look at me and ask 'why?' Say at the beginning, 'Let us know what's important to you guys and don't be afraid to tell us anything because you feel something's going to come back on you. If there is a situation like that, we'll let you know ahead of time.'"*

3. Involve Clients as Much as Possible

It was important to the groups that they are involved early on in the process. One participant suggested that parents are given every opportunity to be involved.

4. Provide Explanations

Both parents/guardians and youth want to know in advance with whom certain information will be shared.

A parent explained: *"Certain things are meant to be shared with certain organizations depending on the situation. However, not everything is meant to be shared with everyone. I'd just like a head's up on who you're sharing with. Why are you sharing that information with that person? I could talk to one person about whatever, and I would think that was just between us; so why are you going to tell another person what's going on? I mean it's my information that you are sending out."*

Discussion

Situational context is important to take into consideration in the building of relationships and leads to open and honest communication that better serves youth and families. Families enter into "unfamiliar agency territory" during a time of crisis; it is important to address discomfort and provide caring acknowledgement and empathy toward the discomfort if a relationship will be created in which accurate information can be shared.

The adult participants emphasized how traumatic the contact with the juvenile justice system and/or other agencies can be for parents/guardians and youth. Many do not know the systems or processes, have feelings of shame, feel they are labeled as "bad" parents, and are fearful that what they say may bring more legal ramifications for their youth, selves, and/or their family.

Parents/guardians are most likely to openly disclose information and authorize its distribution to coordinating agencies if they are properly informed, in a mutually respectful relationship with an agent, understand how their information will be protected, trust that their information will be kept secure, and trust that their information and stories will be used appropriately.

Parents/guardians who contend with youth with mental health and behavioral disorders are particularly concerned with inappropriate disclosure. Appropriate sharing of information is perceived to facilitate access to greatly sought-after but scarce adolescent services and/or treatment. However, it is also important for some of these parents/guardians to have privacy and confidentiality protection to maintain family relationships.

The groups told us that it is important that any shared information be accurate, timely, continually updated, and consistent with the needs of the youth. It must be used in a supportive and not punitive way in true partnership with parents/guardians.

Those who seek information or data need to remember that people from whom they request information choose to be truthful and determine what to disclose to whom and when. Thus, executing their rights and decisions in information sharing, personal explanations will go a long way.

Youth also want to be treated respectfully. While our participants told us a caring relationship and partnership between provider and youth will facilitate more disclosure of information, overall, youth were less willing to disclose in an honest and open manner than their parents/guardians. The youth were more distrustful of the "system" and did not perceive certain shared information as being helpful. In some cases, youth perceive information sharing as doing more harm than good. They are afraid of labeling and getting further in trouble. In addition, youth seem to be more impatient with the system intake processes than their parents are; they want to "play it to get through." Youth want information to protect them but not necessarily to be used to make them "better." This attitude can probably be attributed to egocentric nature of their developmental age.

Study Limitations

We conducted purposeful and convenient sampling from within one state only. Generalizability is not an inherent aim of qualitative study; further studies are needed to assess how representative the findings are of youth and families in other U.S. locales and elsewhere. The adult sample was gender biased. Although both genders were approached to participate, groups were limited by those individuals who actually participated – primarily females. Also, it should not be assumed that the individuals in a focus group are expressing their own definitive individual views. Often they speak in a specific context, within a specific culture, and within a specific group setting; it may be difficult for the evaluator to clearly identify the intent of a specific message. Finally, we must recognize that retrospective accounts of past events can vary with actual events. These findings should be treated as offering actual experiences with some recall bias. Despite these limitations, the discussions provide insight into how youth and families experience and feel about information sharing.

Summary of Youth and Family Recommendations for Information Gathering and Sharing

The focus group discussions provided a wealth of insight from youth and families for the collection and sharing of their information. Some of their suggested *do's and don'ts, below*, were highlighted in more detail previously in this report, while a few others were not.

From Parents/Guardians:

- Be respectful and genuine

- Provide intent from start ("I am here to …")

- Provide more explanation of system(s) processes – *what will happen now, what will happen next, etc.*

- Provide a waiting period during the crisis to allow more understanding and more trust

- Provide a coordinated system across agencies that uses one case manager with a multidisciplinary team

- Place more emphasis on family rather than just on youth

- Partner with families

- Ask only for critical and relevant information

- Ask for information only once, and share with others

- Use simple terminology in speaking and in forms and in materials

- Do not use universal releases

- Provide detailed explanations of why information is needed, how it will be used, and how it will be shared

- Provide consent/authorization forms for sharing that can be used for individual agencies – provide the who, what, when, where, and why

- Provide detailed oral explanations of what they are signing, including how it will benefit or possibly harm; ask if there are any questions

- Keep information updated, accurate, and safe

- Provide checks and balances in JIS

- Provide process for filing grievance or complaints without retaliation

From Youth:

- Treat as unique and not as just another delinquent

- Do not judge, label, or treat disrespectfully

- Be authentically caring and concerned

- Administer assessments once and share

- Ask more *why* questions rather than *what* questions

- Provide more face-to-face contact rather than computer data collection

- Explain in detail why information is being collected

- Ask only for critical and relevant information

- Explain in detail how it will be shared and with whom and why

- Explain orally all forms that require signature

- Do not imply consequences for not signing consents/assents/releases

- Protect confidentiality, especially in school settings

CCYIS - Family & Youth Involvement Subcommittee – Focus Group Guide
(Parent/Guardian Version 3)

Introduction

Introduce facilitators and provide brief description of the Collaborative and the CND.

You have been invited to this discussion because you have or are a parent or guardian of a youth who is or has been in the juvenile justice system and maybe other systems. We know it has not been easy for you or your families. Thus, we thank you for coming here to talk with us.

We are conducting youth and parent/guardian groups. The purpose of this group is to listen and learn from you about your experiences giving personal and sometimes sensitive information to officers or others about you or your youth and family on intake or at other times during the processing. We are especially interested in how you feel about juvenile justice and other agencies sharing this information among the different agencies that may provide services to you or your youth and family.

First, some ground rules for the group: It is important that you know that what you say in this group will not be repeated with any names attached. We hope to use this information to improve how agencies ask for information, better ways to protect this information, and how agencies can share this information in a way that parents/guardians/youths are comfortable.

We agree today to:

- Not to disclose any names or personal information you share.

- Ask that you respect others' confidentiality by not repeating what is said.

- Write a report about this discussion and others and distribute to the CCYIS, the CND who is helping us gather this information, and the Office of Juvenile Justice and Delinquency Prevention, the federal agency funding this improvement.

- Not to put in the report any names or identifying characteristics about the families who participate.

- Ask you to complete an anonymous information sheet that will give us general information about you. Please do not put your name on this sheet.

- Tape record this meeting so we have accurate documentation of what is being said. Please use first names only when speaking to another person within the group. At no time do we want to be able to identify the speakers on the tape. We will have these tapes transcribed, and these transcriptions will also not have any names attached.

- Ask you to please speak one at a time, so that the tape recorder can record what individuals are saying. It is hard to get your great insights when you or others are speaking at the same time. Please be courteous of others.

Do you have any questions before we start?

Focus Group Questions/Probes:

The topic we want to get some help with is sometimes hard to "grasp." So I would like to clarify with you what we mean by agency information sharing.

Children/youth who have committed juvenile offenses are usually involved in multiple systems (i.e., child welfare, juvenile justice, education, mental health, or health, etc.). Providers from these different agencies are better able to meet the needs of these youth and/or their families when relevant and necessary information is shared among them. Services can be coordinated better and be more efficient. So what we mean by "information sharing" is information about you which, let say, the police shares with the juvenile assessment center, or a juvenile assessment center shares with mental health or diversion, or schools share with a juvenile case manager, etc. Sharing happens between agencies.

Let me give you an example….youth and/or families, as you probably experienced, are often given different assessments, questionnaires, or interviews seeking information when they first enter the system. As the youth and families move to another service agency or provider they are often given the same assessments or questionnaires to fill out again. This way of collecting information in which they both need does not seem very efficient. It wastes youth and family time. What we would like to do is create an electronic system in which youth/families no longer have to complete the same assessments more than once. In this case, an electronic system would allow the sharing of this information when completed the first time between agencies who need it in which youth and families are engaged.

To make it simpler, we hope, here's a situation:

Your {son/daughter or self} told the police officer when taken into police custody that he/she is thinking of hurting him/herself. The police officer after talking with you as a parent understands that your son/daughter has tried to hurt him/herself before. The police officer feels that this is important information they and others need to know for taking care of your son/daughter while being processed through the system. Thus, the officer wants to share this information with the juvenile detention or community intake/assessment officer who can facilitate proper precautions. Now the judge decides that your [son/daughter or self] would probably do better in diversion that offers a substance abuse program, so he/she plans to release you or your son/daughter from detention. The releasing detention officer still worried about you or your son's/daughter's well-being wants to share that you or your son/daughter expressed thoughts of harming yourself or him/herself with the diversion officer. The diversion officer wants to also share this information with the substance abuse program. This potential sharing of information across services is meant to protect your or

your son/daughter from actually hurting yourself or him/herself by getting you or him/her help. So you or your son/daughter when entering each of these programs will most likely take the same "harm to self" assessment over and over.

Currently, there is no easy way of sharing this information between agencies. Even though the agencies want to share information, they still need to get your approval and consent to do this. We are now thinking of ways to improve the consenting process and the sharing of information across agencies. That's why we need your help.

1. When you [your child] first entered the system, you or he/she and maybe yourself gave personal information at intake.

   Can you tell me what you thought this information was for?

   Can you tell me where you thought the information went?

   Can you tell me where it might have actually went?

Continued

2. How did someone explain to you how your information would be used?

   Did someone explain to you about your rights or "rules" in having information shared?

   Did you provide information that you thought might not have had to or were not required to because of these rights?

   Did someone explain to you how your information might be shared?

   How was this done?

   Did this make you comfortable or uncomfortable when deciding to share your personal information? Why?

   Do you remember signing something about the use or release of information?

3. What information were you comfortable sharing? Why?

   What were you not comfortable sharing? Why?

   What information did you assume would get passed on?

   What information did you assume would not get passed on?

4. Can you give me examples where agency sharing of information has helped you or your youth or family make progress through the system?

   Can you give me examples where agency sharing of information has delayed or harmed you or your youth or family in these systems?

   Tell me what you understand about a "universal release" to share information.

   Like a form you might have signed in a doctor's office allowing them to share your medical information with whoever needs to know… insurance companies, etc.

   How would you feel if justice system, or the information sharing system that we are trying to set up used a similar universal release?

   Example, principal has a hard time with a student, calls police, police takes him to an assessment center where he is accessed as not a high risk. Though the school wants a copy of this assessment of "not high risk", the assessment center can't share this without your consent this one time. With a universal release they could.

   What else is there that you think we should take into consideration when agencies share information about youth and families?

Closing

Thank you again for coming and sharing your experiences and insights. You bring a lot of expertise to the table. We hope that your presence here will result in some changes that will benefit both the agencies serving the youth and families but also for you or your youth.

CCYIS – Family & Youth Involvement Subcommittee – Parent/Guardian Information Sheet (Version 2)

1. How old are you? _____

2. What is your gender? o Male o Female

3. How do you best describe yourself? *(Check only one)*

   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Hispanic or Latino
   o Native Hawaiian or Other Pacific Islander
   o Non-Hispanic White

4. Are you now employed full-time, part-time, not employed, or retired?

   o Full-time   o Not employed
   o Part-time   o Retired

5. Including yourself, how many live in your household? _____

6. What is your marital status?

   o Single/never been married
   o Married
   o Separated
   o Divorced
   o Widowed

7. Total number of children in the family? _____
   (Include all children, even those living away from home)

8. What is your total household income, including all earners in your household?

   o Under $20,000/year
   o Between $21,000 – $29,000/year
   o Between $30,000 – $39,000/year
   o Between $40,000 – $49,000/year
   o Between $50,000 – $59,000/year
   o Between $60,000 – $75,000/year
   o Over $75,000/year

9. What is the primary language spoken at home? _____

10. What is your level of education completed?

    o No schooling completed
    o Two-year college degree
    o Less than middle school
    o Four-year college degree
    o Less than high school
    o Graduate degree
    o High school/GED
    o Other: _____
    o Currently in college

11. Please check what agencies your child (one involved in justice system) is currently engaged with? *(Check all that apply)*

    o Child Welfare/Social Services
    o Juvenile Justice
    o Mental Health
    o Education
    o Developmental Disabilities
    o Substance Abuse Treatment
    o Other: _____
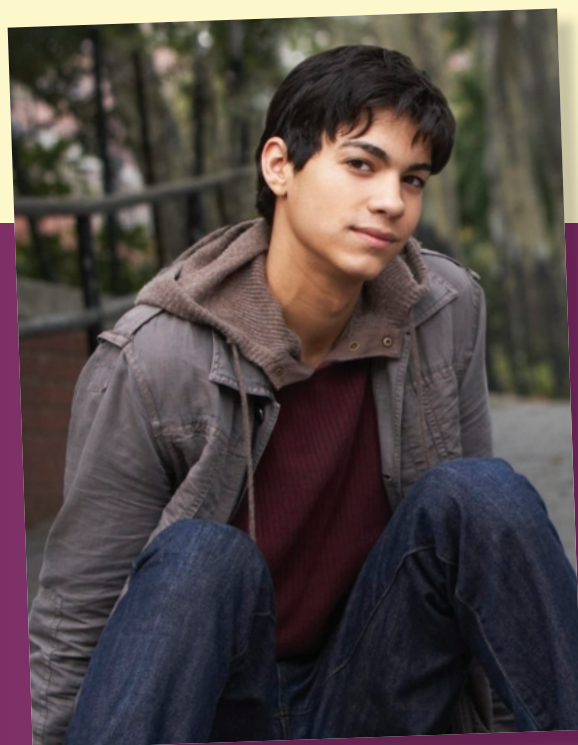
CCYIS – Family & Youth Involvement Subcommittee – Youth Information Sheet (Version 2)

1. How old are you? _____

2. What is your gender? o Male o Female

3. How do you best describe yourself? *(Check only one)*

   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Hispanic or Latino
   o Native Hawaiian or Other Pacific Islander
   o Non-Hispanic White

4. Including yourself, how many live in your household? _____

5. If you know, what is your total household income, including all earners in your household?

   o Under $20,000/year
   o Between $21,000 – $29,000/year
   o Between $30,000 – $39,000/year
   o Between $40,000 – $49,000/year
   o Between $50,000 – $59,000/year
   o Between $60,000 – $75,000/year
   o Over $75,000/year
   o Do not know

6. What is the primary language spoken at home? _____

7. Please check what agencies you are currently engaged with? *(Check all that apply)*

   o Child Welfare/Social Services
   o Juvenile Justice
   o Mental Health
   o Education
   o Developmental Disabilities
   o Substance Abuse Treatment
   o Other: _____

[1] *Guidelines for Juvenile Information Sharing* (2006), USDOJ, OJP, OJJDP Report: NCJ:215786.

[2] Rondenell, S., Duclos, C., and McDonald, J. (2011) *Governance Guidelines for Juvenile Information Sharing.* USDOJ, OJP, OJJDP Report.

[3] Crabtree, B. and Miller, W. (1999). Using codes and code manuals: A template organizing style of interpretation. In *Doing Qualitative Research.* B. Crabtree and W. Miller (eds). Thousand Oaks, CA: Sage Publications, Inc. pp. 163-177.

Notes