Starting the conversation:

Do you want to talk about your child?

***MANUAL***

For program facilitators and participants

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Starting the Conversation (STC) is derived from the Honest, Open, Proud program, formerly known as Coming Out Proud to Eliminate the Stigma of Mental Illness. For information, contact Patrick Corrigan ([Corrigan@iit.edu](mailto:Corrigan@iit.edu)) or visit the website at [www.hopprogram.org](http://www.hopprogram.org) Version: 07/2017

**TABLE OF CONTENTS**

**Lesson 1. Considering the Pros and Cons of Disclosing9**

1. Stigma affects children *and* their parents9
2. Considering how this might impact you……………………………………...12
3. Consider the pros and cons of disclosing17

**Lesson 2. There are Different Ways to Disclose25**

1. Different ways to disclose25
2. How might others react?31
3. Developing your coping plan33

**Lesson 3. Telling Your Story36**

1. What would you like to say? Disclosing from a position of strength36
2. How would you like to disclose? 39
3. Try it out 40
4. Putting it all together41
5. Looking ahead42

**Final Session. 43**

1. Who did you intend to talk with, and who have you talked with?43
2. Where to find support47

**Appendix 1**. Challenging Personally Hurtful Self Stigma50

## PREFACE

This is the companion manual to the ***Starting the Conversation (STC): Do you Want to Talk About Your Child?*** workbook. The program is meant to be flexible and can be done in different formats based on feedback received from *STC* facilitators. For example:

* *STC* might be completed as a day-long seminar of about 6 hours with a 2-hour ‘final session’ about one month later.
* It can be done as three 1.5 to 2-hour sessions that includes the ‘final session’ about 1 month later (as outlined in the Table of Contents).
* *STC* can be administered in 7 sessions of up to 1 hour, with each corresponding to 1-2 tasks under each lesson.

Facilitators should decide among these options based on the needs of program participants.

In this manual, lessons/tasks are laid out with learning points, discussion questions, and group exercises. Individual lessons directly correspond to sections of the program manual. This program is best run with 4 to 8 participants. One or two people should facilitate, preferably people who are or have been parents/caregivers of children with mental health challenges. All that is needed to run this program is a private room, manuals for the facilitators, and paper copies of the workbook for each participant. All materials in this manual and in the program workbook can be downloaded for free on the program website ([www.hopprogram.org.](http://www.hopprogram.org.)).

***A Little Bit of History***

*Honest, Open, Proud* started as a chapter on disclosure in Corrigan and Lundin’s

*Don’t Call Me Nuts: Coping with the Stigma of Mental Illness* (*DCMN*; published by Recovery Press, Tinley Park, IL, 2001). Corrigan and Lundin, a service researcher and a consumer, respectively, were an energetic team that combined their wisdom into a practical text (*DCMN*) meant to address stigma change. In 2011, they began an effort to update the chapter into a stand-alone program with two overarching goals governing the task. First, they sought a panel of people with mental illness to review the program for relevance and utility, in the process asking them to try out program components. Second, they sought to do this with a collaboration of partners from around the globe. Their intent was to construct a program with some attempt at cultural sensitivity and relevance. As such, the initial HOP program was created for adults with mental illness. They have thus far received feedback from people with lived experience in Australia, Germany, Switzerland, the United Kingdom, Canada, and the United States.

This version of the program you are reading – ***Starting the Conversation (STC): Do you Want to Talk About Your Child?*** – has been rewritten based on the original HOP program with the help of parents and other caregivers of children who have diagnosed mental health challenges. This was done for parents and caregivers of children with mental health challenges who expressed the need for a program that considered the unique issues of disclosing on behalf of their child. Although we use the term ‘parents’ throughout the program for simplicity’s sake, please note that this term is intended to refer to any caregiver of a young child with mental health challenges.

***An Important Note.***

Please note for everyone in your group that they should find out about what laws, regulations, or policies (etc) exist around disclosure for a child’s diagnosis in their particular situation. For example, disclosure might be needed to gain access to services for a child, or might be legally required in some situations (e.g., field trips that involve overnight stays). This Manual and the Workbook do not comment on these, and can’t be held accountable for these.

***Two Rules for Deciding About Disclosure***

Corrigan and Lundin propose two overall rules to guide any consideration of strategies for disclosing mental illness. Rule 1 suggests caution. To paraphrase an American Supreme Court Judge, “*It is hard to quiet the clanging bell.*” The truth can be glaring. Once you have disclosed, it is very difficult to retract the news. According to the *Rule of Minimal Risks with Little Information*, disclosing and then recanting is much harder than being conservative and letting people know slowly. Rule 1 counsels overall caution in disclosing such private information.

On the other hand, Rule 2, *Delayed Decision is Lost Opportunity*, suggests caution leads to unnecessary delay. There will always be hostile and ignorant people who will chastise you for talking about your child’s mental health challenges. Don't let them keep you from talking to people who are caring and supportive.

Although these rules represent wise advice to guide this tough decision, they obviously contradict each other. That's because there is no clear answer to the question about disclosure. Only you can know for sure what the right decision is for you and your family. You must weigh all of the costs and benefits and decide for yourself what to do.

***About Language***

This manual is written directly for parents of children with mental health challenges. Hence, instead of the third person language that typifies most programs and manuals, we write the document in first (I and me) and second (you) person language, hereafter. Telling others about a child’s mental health challenges (i.e., disclosing) is a personal decision. Thus, this manual is written in like fashion.

A second consideration about language: the mental health community around the world varies in the way that it refers to children with mental health challenges. “Mental illness,” “psychiatric diagnoses,” “mental health problems,” and “mental health diagnosis” are just a few terms. We use the term “children with mental health challenges.” We adhere to the notion of “*person first*” language. In other words, we refer to people with a condition, not to “*patients*,” “*schizophrenics,*” or “*depressives.*” Person first language stresses the personhood of the individual as primary. Furthermore, we chose *“children with mental health challenges*” based on our belief that it is the child’s mental health challenges that are leading to the parent’s concerns about disclosing. *“Mental health challenges”* was chosen over *“mental illness”* because a child’s diagnosis is not seen as needing to reach the level of a diagnosable illness in order for this program to meet parents’ needs. For example, a parent of an 8-year old child who was diagnosed with depression but no longer meets criteria may still need to make decisions about disclosing the child’s current and past mental health. Participants are encouraged to identify terms -- e.g., mental illness, mental health challenge -- that work for them and their family.

***Workbook***

A workbook has been written as a companion to this manual (*Starting the Conversation (STC): Do you Want to Talk About Your Child? – Workbook*). The workbook briefly summarizes the key points of each lesson, and also provides useful exercises that help participants to make decisions as well as implement actions surrounding/related to talking to others about their child’s mental health challenges. The workbook (as well as additional copies of this manual) are available for free on the “Manual and Resources” page of [www.hopprogram.org](http://www.hopprogram.org)

**Notes to Facilitators:** The manual and workbook are designed to be used together. Before each session, distribute that week’s section of the workbook (not the whole thing) to participants. Note that for the first lesson/meeting, you’ll need to hand out copies of Lesson 1 + the Appendices! The entire workbook is long and can be distracting, and some participants might try to work on it without coming to the group meeting and not gain enough from it.

In the manual, we have written in a “script” of what you could say during each group. You don’t have to say every word exactly as written! Practice it and say it in your own words, at your own pace. You’ll be more interactive, and you – and the participants – will get more out of it. The script gives you an idea of what to say and can be helpful if you feel that reading aloud is better at that moment. Notes are made **in bold**. These **notes** are not to be read at any time. They are instructions to facilitators to do something (e.g., take up a task as a group).

**Acknowledgements**

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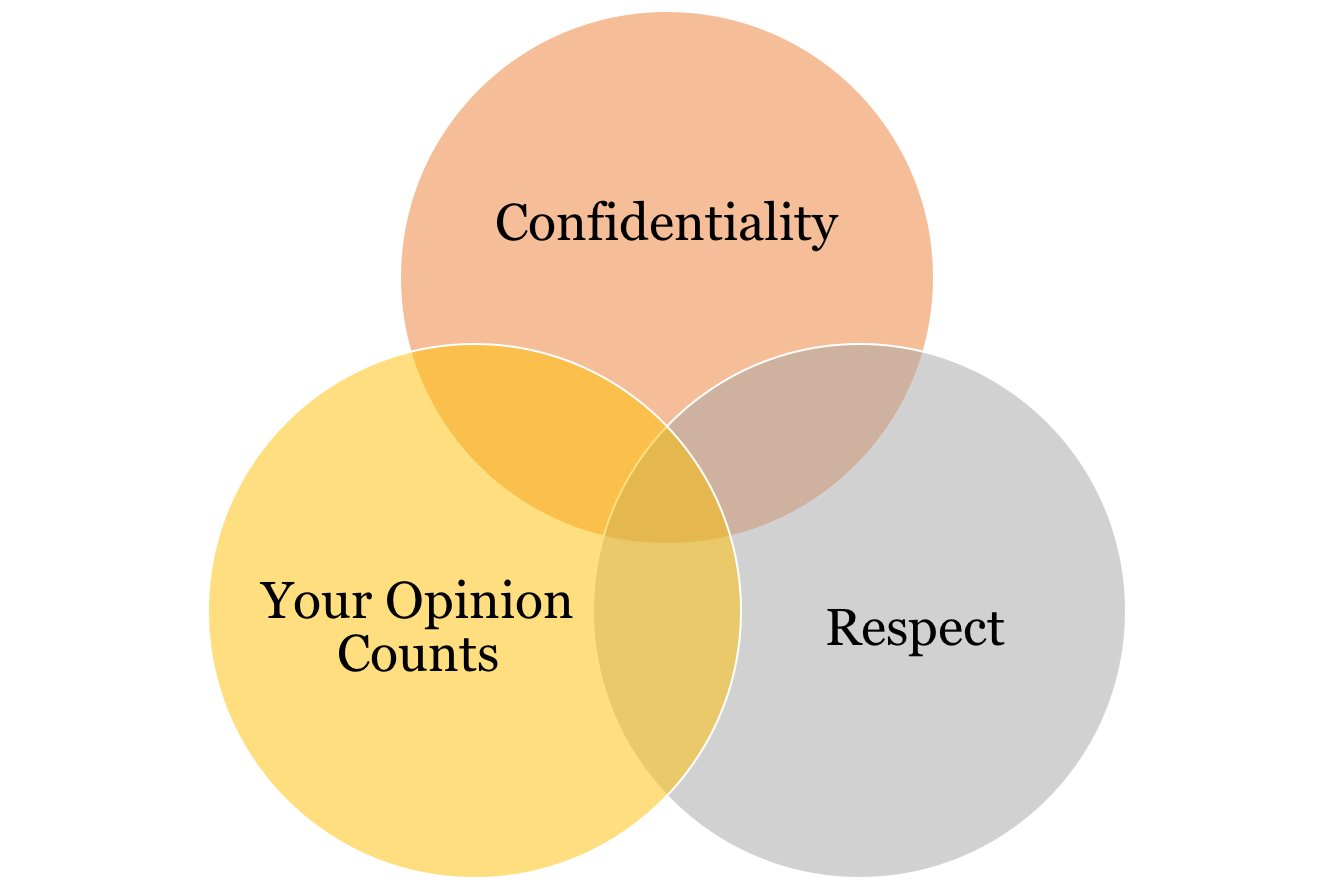
##### Starting Each Lesson

The first thing we want to do at the beginning of each lesson is set the tone. To do this, we start by having facilitators provide their names and any other introductory information they would like to share with the group. Facilitators should then go around the room and ask each participant to share their first name (last names and titles are not necessary unless the person chooses to share this information with the group). After introductions, facilitators should state the overall purpose of the program:

*“Our goal here is to consider what the costs and benefits are of disclosing a child’s emotional or behavioral challenges to some people. We also seek to discuss strategies for disclosing most effectively should you decide to do so.”*

Facilitators should also establish some general ground rules with the group:

* Confidentiality- what is said in the room stays in the room,
* Everyone’s opinion counts, and
* We respect each other.

Introductions and ground rules should be repeated at the start of all meetings.

The goal is to create an open environment where people feel comfortable sharing their opinions and feelings should they choose to do so.

# LESSON 1

## Considering the Pros and Cons of Disclosing

LESSON OVERVIEW

Openly discussing your child’s mental health challenges is the right decision for some people, but not for everyone. This section is a guide to help parents decide which decision is right for them. We approach the decision in three parts:

1. We discuss how both children and their parents are harmed by stigma.
2. How this might impact you?
3. We help you weigh the costs and benefits of disclosing your child’s challenges to others, so that *you* can decide whether or not to disclose.

**Task 1. Stigma Affects Children *and* their Parents.**

LEARNING OBJECTIVES

* Think about how *both* children with mental health challenges *and* their parents can be targets of stigma
* Consider how parents would like to label their child’s current challenges

This lesson is about considering the benefits (pros) and costs (cons) of telling other people about (“disclosing”) your child’s mental health challenges. Making this decision is complicated.

One of the reasons why parents do not want to tell others about their child’s mental health challenges is because they are afraid of stigma. Stigma can be thought of as negative or unfair beliefs about or actions towards a group of people. Children with mental health challenges can be targets of stigma: for example, a parent may overhear another parent at their child’s school say “this whole ADHD thing is made up… these kids are just lazy.” Parents of children with mental health challenges can also be targets of stigma: for example, others may think that “parents of kids with anxiety are unfit to be parents.” These comments about children and their parents are *unfair, negative,* and *painful.* As a parent, you may be aware of stigmas that exist towards both your child’s mental health problem, as well as parents like yourself. You and/or your child may have even encountered some of these unfair, negative, and hurtful beliefs or actions.

When you are making decisions about whether to talk to others about your child’s challenges, you’ll need to consider stigma towards both you *and* your child, so let’s take some time now to consider some of the stigmas that might concern you. Take a look at Table 1.1. It has listed just a few stigmas about children with mental health challenges in the first column, and a few about their parents in the second column. Have you come across these stigmas? Is there anything that you would like to add?

**Table 1.1: Examples of some stigmas towards children with mental health challenges and their parents. Are there any you would like to add?**

|  |  |
| --- | --- |
| **Stigmas towards *Children* with Mental health challenges** | **Stigmas towards *Parents* of Children with Mental health challenges** |
| “These kids are just lazy” | “These parents are unfit” |
| “These kids shouldn’t be in the same class” | “Parents just want a label so they can get medication” |
| “These kids are a bad influence” | “If these parents knew what they were doing, the problem would be solved.” |
|  |  |
|  |  |
|  |  |

Neither stigma is more or less important than the other. It’s important however, to keep in mind WHICH stigma you are addressing later on.

***Can diagnoses or labels make this worse?***

Sometimes parents are concerned about the diagnosis, or label, that their child has been given because labels can worsen stigma. Words can be powerful and society can stigmatize some terms more than others. For example, people might think of the term “mental illness” as bad, inappropriate, or offensive… But few people would feel this way about “physical illness.” Why is it okay for someone to be physically but not mentally ill? This is because we have stigmatized the words “mental illness” and not “physical illness.”

There are many ways that we talk about mental health challenges. In this program, we will use the term “mental health challenges” because most parents prefer that term. You may prefer a different term. This might be a diagnostic label, like “ADHD,” or it might be a description, like “he/she is inattentive.” You can let others in the group know how you would like to refer to your child’s challenges.

**Let’s read about Michelle and Jason’s stories.**

**Michelle** is 32 years old and has a son who was diagnosed with *attention-deficit/hyperactivity disorder—inattentive type* last year*.* **She refers to his challenges as “A.D.D.”** when she talks to others about her son’s difficulties.

**Jason** is also 32 years old, and has a son who was recently diagnosed as having *attention-deficit/hyperactivity disorder—inattentive type.* **He refers to his son’s challenges as ‘inattentive’** when he talks to others.

Neither Michelle nor Jason use ‘ADHD’ to refer to their child’s challenges. However, they have both chosen different ways to refer to similar difficulties.

What term would YOU like to use? Try completing *Worksheet 1.1*.

|  |
| --- |
| **IN THE WORKBOOK:**  ***Worksheet 1.1* (p. 9), *“Finding a term that fits for you”* helps parents consider terms that work for them.** |

**Take up *worksheet 1.1*, Section 1 *‘Finding a term that fits for you*,’ so that the group can discuss their own chosen way of referring to their child’s difficulties Write down everyone’s ideas as they offer them next to their first name. It’s ok if someone hasn’t decided yet. Make sure to write down the term exactly as the parent says it.**

Note that this is not a one-time decision! People might change their minds about how they would like to refer to their child’s challenges.

Note also that this is a decision that should take into consideration any laws, policies, requirements, and so on, that exist in your/your family’s situation. For example, you might be required to disclose in order to gain access to services for your child, or you might be required to disclose in completing school forms (e.g., that ask about diagnoses or needs). Please ensure that each family conducts their own research into what issues impact on them.

**Task 2. Considering How Stigma Might Impact You.**

LEARNING OBJECTIVES

* Some parents agree with stigma that is directed towards them, and beat themselves up as a result.
* Program participants try challenging these thoughts.

There is another reason why we started off talking about stigma towards children and their parents. This is because parents can take the stigma that they are aware of, and believe it about themselves.

For example…

* Parents of children with depression are doing a **bad job of parenting**.
* Parents of children with ADHD choose medication because **they are being lazy**.
* There is **no such thing** as separation anxiety disorder. These parents are **over-reacting**.

Stereotypes like these are in the same immoral class as racist, sexist, and ageist comments. Unfortunately, some parents of children with mental health challenges agree with stigmatizing beliefs like these and internalize them.

For example…

* I have a child with depression, so I must be doing a **bad job of parenting**.
* Choosing medication for my child was choosing the **lazy way**.
* There is no such thing as a separation anxiety disorder, I’m just being **over-reactive**.

### This is called Self-Stigma.

### *Challenging Personally Hurtful Self-Stigma*

Do you have personally hurtful beliefs like these? Ask yourself, in moments that are really tough as a parent, what thoughts do you have about yourself? If some of these seem like self-stigma, then write them down here... and we will think about a way for you to challenge it.

**Now give participants some time to try writing down any thoughts that they might have – even if they don’t have them now or haven’t had them recently, they can offer ones that have been hard in the past. There is space for them to write these in thought bubbles on p.11 of the workbook**.

**When participants have done this, say:**

Just like stigma that others hold, this is painful and unfair to you.

Let’s look at 5 steps to changing this. If you don’t have any hurtful thoughts, then you can help as we go… if you ever need to challenge thoughts like this in the future, you’ll know how!

**Step 1.** Begin with a **clear statement** of the hurtful attitude you are holding like this:

***I must be*** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ ***because*** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ .

e.g., John’s statement: “*I must be* ***a weak or incompetent parent*** *because* ***my child has anxiety***.”

e.g., Judith’s statement: “*I must be* ***a bad parent*** *because* ***my child has ADHD****”*

**Step 2.** The next step is to really look closely at this stigma. Change it into a true-false statement about parents in general.

For John’s example above:

*Only parents of children with anxiety (or other challenges) are weak and incompetent. Parents of children without anxiety never feel weak or incompetent due to their challenges.*

If you believe this, you will feel worse about yourself.

For Judith’s example, what would it be?

**Now encourage parents to think of a statement or two, and write it on the whiteboard… e.g.,**

**Parents of children with ADHD are bad parents because they have caused their child’s ADHD.**

**Step 3.** One way to challenge assumptions like these is to **look for evidence**. You could ask others you trust if they believe them to be true. If others you trust don’t hold these beliefs, then that is good evidence for you to reject your thought.

For example, John could seek out some people he trusts – a close friend or cousin. These people might say that parents of even the ‘best behaved’ kids struggle and feel ineffective. Maybe they have sought help from others at times, perhaps their family doctor, a counsellor, or self-help books.

Similarly, Judith might ask her GP about the causes of ADHD because she trusts her GP to know about the science behind what causes ADHD. Her GP tells her that there is no evidence that ADHD is caused by parenting.

**Step 4.** This step is to pause and **look at the evidence** you have gathered. In other words, after talking with these trusted people you might find that your hurtful belief (for John, *that parents of children without anxiety never feel weak or incompetent due to life challenges*) is not true.

**Step 5.** The final step is to use your findings to **develop a new attitude** that ***counters*** (or is contrary to) the hurtful belief.

For example:

“*I'm not a bad parent for feeling weak. Every parent does at times.*”

What could Judith write? **Ask participants for ideas, and write down one on the whiteboard; e.g., “I’m not a bad parent because my child has ADHD. ADHD is not caused by bad parenting.”**

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Maybe write the ‘counter-belief’ down on a card so that you remember it better (an example is given below). The next time that you feel bad for weakness, pull out the card. Remind yourself that every parent feels weak once in a while.

Date:

**COUNTER TO:**

I AM WEAK!

Would this exercise help **you**?

Look in the Appendices… Appendix 1 on page 63 helps you with this.

If you have personally hurtful self-stigma, then consider completing this exercise. You’ll find another example of Alan challenging his hurtful self-stigma thought: It is shameful to have a child with mental health challenges, AND you will find worksheets to help you through this process.

Holding on to your ‘counters’ can help you in the future… whether or not you decide to disclose!

**Task 3. Considering the Pros and Cons of Disclosing**

LEARNING OBJECTIVES

* There are both benefits and costs to disclosing – and not disclosing – your child’s challenges.
* Only *you* can weigh them to decide whether the pros outweigh the cons.
* Costs and benefits differ depending on *who* you are telling.

|  |
| --- |
| **IN THE WORKBOOK:**  ***Worksheet 1.2,a* (p. 16), *“Pros and Cons of Disclosing”* and *Worksheet 1.2b, “Pros and Cons of not Disclosing”* gives participants an opportunity to develop their own reasons for/against disclosure (and not disclosing).**  **Tables are provided to list the costs and benefits of disclosing and not disclosing (see *Table 1.3 and 1.4*).**  ***Worksheet 1.3* (p. 21), *“The Costs and Benefits Worksheet for Disclosing My Child’s Mental Health Challenges”* provides a way to lay out the short- and long-term costs and benefits of disclosing in different settings and to different people. This worksheet is designed to help participants make decisions about how they would like to move forward with the issue of disclosure.** |

***Before you all begin…:***

**Note that now is a good time to acknowledge that there might be some parents for whom disclosure isn’t a question – they need to. For example, parents of children with autism. However, even for them, they do make some decisions, such as whether or not to disclose a fear or depression, or whether or not to tell others who don’t see their child much (e.g., a co-worker or a manager at work). You could start with something like this:**

*First,* you may feel that disclosing isn’t a decision you can make because your child’s behavior might be such that you need to talk to others about his or her challenges. If this is the case for you and your child, know that you still make certain decisions around disclosing. You might decide how much to tell; for example, you might tell about some social troubles but not about your child experiencing bullying a few years ago or having bedwetting. In some cases, you may decide who to tell – for example, a co-worker might not know or need to know, but you might decide to tell him or her anyway. You also make decisions about how to tell these other people even if you need to, and we’ll talk in later meetings about how you would like to tell others in a way that advocates for your child.

If you are a parent who needs to disclose, you may want to think about some of your child’s challenges, such as an anxiety, that you haven’t yet disclosed as we go on. Or, you may simply wish to listen now in case this becomes something you face in the future as your child grows and changes. You might have a lot of experience that you can help out the group with, too.

***Reasons to tell others (disclose)***

There are lots of reasons why you might **choose** or **not choose** to disclose your child’s challenges. Some reasons affect the parent, others affect the child, and still others affect the parent and the child. For example, you don’t have to worry about hiding your child’s challenging behavior, like you might think “*Wow, I used to fret about my child’s teacher finding out that I was taking my child from class early to see the psychiatrist. Now, it doesn't matter.*”

Or, you might find that telling your and your child’s story from a perspective of strength may result in advocating for your child’s needs.By explaining your child’s challenges from a position of strength, the teacher or childcare/daycare provider may be able to implement strategies that help your child, or family and friends may be more accommodating; for example, you might be able to say *“Can we come, but 30 minutes late? We really need 30 minutes to relax and have a snack before we do anything else.”*

There are also lots of **reasons not to disclose.** One big reason why you may choose not to disclose is one we’ve been talking about: stigma. For example, some people may disapprove of you and/or your child. They may say something like, “I’m sick and tired of all these kids with “challenges.” I just wish they’d all stop whining about it and just get on with it instead.” Or, people might start talking about you and/or your child. They may have ignorant views about children with mental health challenges being dangerous and want to protect themselves and their children. They may not invite your child for a play or to a party, or discourage their child from playing with yours at school.

Whether you choose to talk with others – or *not* talk with others – about your child’s challenges, there are benefits (or “pros”) and costs (or “cons”) to both you *and* your child. It is your decision.

**The task now is to divide participants into 2 teams and ask them to look at both sides: one team will look at benefits & costs of disclosing, and the other will look at benefits & costs of NOT disclosing. After they have worked on this for about 10 minutes, you can take this up in the whole group. You can say something like:**

What we’ll do now is to go through some benefits and costs of telling others – and not telling others – about your child’s challenges. Let’s have this side of the room work on disclosing – *Worksheet 1. 2a –* and this side work on not disclosing – *Worksheet 1.2b.*

**There are ideas below in table 1.3 and in case ideas will be helpful to get the group started AND at the end of the task to make sure the list was comprehensive. These can also be ‘flipped’ to provide reasons for/against not disclosing.**

|  |  |
| --- | --- |
| ***Table 1.3: Some Costs and Benefits of Talking with Others about Your Child’s Challenges*** | |
| **Benefits** | **Costs** |
| You don’t have to worry about hiding your child’s challenges. | Others may disapprove of your child’s challenges, or that you talk about it. |
| You can be more open about your day-to-day experiences. | Others may gossip about you and/or your child |
| Others may express approval. | Others may exclude you and/or your child from social gatherings. |
| Others may have similar experiences. | You may worry more about what others think about you/your child. |
| You may find someone who can help you in the future. | You may worry that others will pity you. |
| You are promoting your sense of personal power. | Family members may be angry that you talked about your child’s challenges. |

**Now have participants talk about their list of benefits in Table 1.3, encouraging them to think about both themselves and their child. What stood out?**

**As they do so, create a “Master List” of “Benefits of Disclosing” on a whiteboard. Participants might like to write down anything else that is relevant to them.**

***Putting it all together: Weighing the Costs and Benefits of Disclosing***

Now you have a good list of benefits and costs of telling others or not telling others about your child’s challenges. Only you can judge what the costs and benefits are of your decision.

This is a general list, though, and you may find that your decision may be different for different people in your life and your child’s life. For example, the benefits and costs of having a conversation about your child’s challenges with their school teacher or childcare/daycare provider may be quite different than the benefits and costs of the same conversation with your close friends. You might come to the same decision, or you might come to different decisions.

We have given you a few *Costs and Benefits Worksheets for Discussing my Child’s Challenges* worksheets (*Worksheet 1.3*) to help you make this decision for each of the different people in your life. You can do these at home.

But first, we want you to consider some other issues:

**1. Your decision depends on who you are thinking of talking with**.

As we were just talking about, telling your child’s teacher is different from telling your child’s soccer coach. You don’t have to tell everyone; you can tell some and not others. When you make your decisions, keep the setting in mind, as in some places (e.g., your child’s school), discussing your child’s challenges might result in others knowing as well. You can ask for confidentiality, but you might not get it. This might be different in other places, where it is easier to tell one person and not others in the same setting. For example, you might discuss some challenges you are having with one parent of another child in your child’s class whom you are close to, but not others.

**2. Short- and Long- term thinking.**

Some benefits and costs are short-term – for example, if you discuss your child’s difficulties with his/her teacher, the teacher can help now to put strategies in place (benefit) but you may fear judgment from the teacher (cost). Others are long-term – for example, if you tell your child’s teacher then the extra resources could help your child succeed at school (benefit) but you also need to consider that your child’s difficulties (which you may feel are private and confidential) might be discussed with other school staff (cost). Similar benefits or costs may be true with your child’s daycare/childcare provider.

People tend to be more influenced by short-term costs and benefits because they happen sooner… but long-term costs and benefits often mean more for the future. So, make sure you carefully consider those as well.

**3. You don’t have to tell everything.**

You can decide if you want to tell someone many or few details… or something in between. Deciding to disclose doesn’t mean you need to talk to everyone about everything.

**4. Don't dismiss any cost or benefit no matter how silly it may seem*.***

Put them **all** on the list so that you can consider all advantages and disadvantages together. Sometimes the items that you want to censor are actually important; you may just be embarrassed about the issue. Know that, if the item is really irrelevant, you'll ignore it when you make a final decision.

**5. What is your goal in disclosing?**

After weighing the costs and benefits you listed, review what you found to be important in *Worksheet 1.2a (Some Reasons Why Parents Decide to Disclose Their Child’s Challenges).* These reasons may have changed as you considered more costs and benefits of disclosing. When you talk about your child’s challenges to this person, what do you want? Are you disclosing to address child stigma or parent stigma? Write your goal in the box – *What is your GOAL in disclosing? –* at the bottom of *Worksheet 1.3.*

**6. Disclosure is beginning a conversation**.

Disclosure is not a “one-time thing.” It’s also not about “telling” or “talking at” a person; it is about beginning a conversation. For example, if you decide to talk to your child’s teacher or childcare/daycare provider, then you’ll open up some future conversations about your child’s symptoms, how he/she is doing in the classroom in light of what you have discussed, and so on.

After listing all the costs and benefits, put a star next to one or two that seem to be particularly important. Important items are the ones you spend a lot of time thinking about. You may want to star (\*) the items that make you nervous when you think about them. Or, you may mark items that suggest a lot of hope.

**What is your decision**? The purpose of *Worksheet 1.3* on page 21 is to decide about whether or not to talk about your child’s challenges with others.

On the worksheet, you will see a decision you can make:

* Yes, I want to let this person know about my child’s challenges
* No, I don't want people to know about my child’s challenges
* I’ve decided to put off my decision until later.

There is no easy way to add up the costs and benefits and come to a decision. Good decisions are more than a sum or tally of the ‘costs’ and ‘benefits’ columns in the worksheet. Some benefits and costs will be more important to you, and should influence your decision more strongly.

Some people may not be able to make a decision about disclosing after reviewing costs and benefits; you may need to decide to postpone your decision. You may choose to use this additional time to gather more information, or to talk with others you trust. Remember that if you decide to ask someone else for his/her opinion, you will need to disclose to him/her, and this person will likely ask you what you decided to do.

Your interests in disclosing are going to change over time and this will depend on lots of things. Your child is developing and changing constantly, which may influence your decisions. Also, your child may develop different symptoms, or begin a different treatment that might change your mind or change the need for you to disclose.

For example:

*“You know, after my daughter developed separation anxiety on top of the depression she’s experienced, I decided to talk to her teacher about what it means for dropping her off in the morning.”*

Conversely, you may decide to disclose today, but pull back later.

For example:

*“I let my child’s teacher know last year, and talked with her several times. But it’s just the beginning of this year, I’ll see how it goes before I discuss more.”*

**HOMEWORK**

There are a few copies of *Worksheet 1.3* for you to do as homework, and you can make as many more as you like. Think of someplace or someone currently important to you to whom you might disclose. This homework is given to you for the purpose of helping you make a decision, you are not expected to turn it in or share it with anyone. You may find yourself filling out the *Costs and Benefits Worksheet* several times in your life and coming up with different conclusions each time; that’s okay. Appendix 2 of the workbook has five blank copies of *Worksheet 1.3* for you to complete in the future.

Here are some people you may wish to complete a worksheet for: your child’s teacher, people who provide childcare for your child (e.g., afterschool care, daycare), your own close friends, other parents in your child’s class, your child himself/herself, your other children, your parents, your siblings.

Next week, we’ll talk about different ways to disclose your child’s challenges to those you decide to talk to.

# LESSON 2

## There are Different Ways to Disclose

LESSON OVERVIEW

It might seem obvious, but there are different ways to talk about your child’s challenges.

1. We describe five ways here, and then guide you through considering the costs and benefits of each.
2. We then consider how others might respond to what you have to say
3. We then make a coping plan for how to handle others’ negative reactions.

### Task 1. Different Ways to Disclose

LEARNING OBJECTIVES

* Parents might disclose their child’s challenges and treatments in different ways.
* Understand the costs and benefits of disclosing in the five different ways.
* Remember, you will perceive different costs and benefits associated with each of the five ways. The costs and benefits you identify may vary by setting.

|  |
| --- |
| **IN THE WORKBOOK:**  ***Table 2.1* (p. 24) *“Five Ways to Talk (or Not Talk) about your child’s challenges”* summarizes the five ways people might** **disclose their child’s challenges.**  ***Worksheet 2.1* (p. 26), *“Costs and Benefits of the Five Ways to Disclose”* provides a way to lay out the costs and benefits of the five ways of disclosure at a place of your choosing.** |

Last week, you completed *Worksheet 1.3,* and decided who, if anyone, you would like to talk with about your child’s challenges. You may have come to the decision to talk with nobody, to select a few people to talk with, to tell most people, or even to be very open to everyone about your child’s challenges.

These different options are listed below in *Table 2.1* of your workbook, and on the next page there is a helpful picture of these 5 ways. For example, some parents may choose to selectively tell others in certain situations (e.g., tell my church group and child’s teacher), to keep it a secret in other situations (e.g., not tell co-workers), and to avoid a third set of situations altogether (e.g., not talk or socialize with other parents of children in my child’s class).

**Here are the 5 ways to Disclose/Not Disclose in case they are needed. You do NOT need to read these aloud:**

|  |  |
| --- | --- |
| ***Table 2.1: Five Ways to Talk (or Not Talk) about Your Child’s Challenges*** | |
| **1. SOCIAL AVOIDANCE: Not tell anyone about your child’s challenges and avoid situations where people may find out about it. Because this would include school, you might decide to home-school your child.** | |
| **Benefit**: You don’t come across people who will unfairly harm you and/or your child. | **Cost**: Isolating yourself and your family. Difficult and stressful to do with children, as you cannot control their symptoms in all places. You might be put on the spot at your child’s school and need to discuss it. |
| **2. SECRECY: Participating in work and community situations, but keeping your child’s challenges a secret** | |
| **Benefit:** Like social avoidance, you withhold information about your child’s challenges. But, you don’t avoid important settings like your child’s school, so you can achieve advocacy there. | **Cost:** Some people feel guilty about keeping secrets. You may also receive less support from others because they are unaware of your child’s difficulties. |
| **3. SELECTIVE DISCLOSURE: Disclosing your child’s challenges to selected individuals, like their teacher and your close friends, but not to everyone.** | |
| **Benefit:** You find a small group of people who will understand your experiences and provide support. This enables broader advocacy for your child. | **Cost:** You may disclose to some people who then hurt you with the information. You may have difficulty keeping track of who knows and who doesn’t. |
| **4. INDISCRIMINANT DISCLOSURE: Making the decision to no longer conceal your child’s challenges; this does not mean, however, that you are telling everyone everything.** | |
| **Benefit**: You don’t worry who knows about your child’s challenges. You may find people who will be supportive. You may find advocacy easier. | **Cost:** You may tell people who then hurt you with the information. |
| **5. BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people about your child’s challenges.** | |
| **Benefit:** You don’t have to worry who knows what. You are promoting empowerment, and a personal sense of empowerment in yourself. You’re striking a blow against stigma. | **Cost:** You are going to encounter people who try to hurt you with this information. You are going to meet people who disapprove of your decisions. |

***What did you decide?***

Look at *Table 2.1.* Did you choose selective disclosure – that is, did you decide to talk with some people but not everyone in the worksheets you did for homework? Or did you choose social avoidance – that is, did you decide to tell nobody, and to limit you and your child’s activities in order to avoid social situations in which others might find out? Or did you choose one of the other options?

Take some time now to look at your *Worksheets 1.3* and circle what you chose to do. Let’s talk about the pros and cons of each.

**Pause for participants to do this. The next task will be for parents to write down their own ideas as you talk about these different strategies for a while.**

If you look at *Worksheet 2.1* (p. 26)*,* you will see a costs and benefits table for each of the different strategies. I will talk about each strategy now, and give you some examples of what other parents have found. As I do this, write down some of the pros & cons of the five ways to disclose that are most key for *you and your family*.

1. ***Social Avoidance***

One way to handle disclosure may be to not tell anyone. This is difficult to do with children, as parents can’t entirely control their child’s behavior in different places and so this may mean avoiding school and home-schooling instead. In other words, you might avoid situations where people may find out about your child’s challenges.. Some parents may not have this as a choice, as their child’s behavior might mean that they need to tell others about their challenges.

There are major negatives to social avoidance. You will lose the benefits that talking with others brings, such as free access to a broader set of opportunities and others who support you and/or your child. Parents who choose to avoid social situations may be putting off a challenge that they and their children must eventually face, such as if the school calls with an emergency related to your child’s difficulties. Still, one benefit might be that social avoidance is a useful strategy during times when a child’s symptoms are intense and he or she needs a respite from the demands of society for a brief time.

1. ***Secrecy***

There is no need to avoid everyone at all times in order to keep your child’s challenges private. Having said that, you can’t control your child’s symptoms, so you need to think about times and places that are best to engage in or with (i.e., times when and places where your child is less likely to show his/her symptoms). For example, some children do better first thing in the day, whereas later in the day their symptoms are more likely to show. Again, as with secrecy, you may not have this as an option if your child’s behavior might mean that you need to tell others about his/her challenges.

An advantage of secrecy is that it minimizes stigma; as one mother commented, *“Back at the start I didn’t disclose much at all… there was quite a bit of stigma.”* Keep in mind that one possible effect of keeping your child’s challenges a secret from everyone is that your child may grow to feel ashamed of his/her symptoms.

You may wish to talk to your child about what he/she would like to say to his/her friends, too. At first, this may be difficult to talk about… but keep in mind that by talking about this with your child, you are teaching him/her about making disclosure decisions by talking with a trusted and loving person (YOU).

1. ***Selective disclosure***

When you keep your child’s challenges a secret, you are not able to make use of the support and resources of others. Some people take a chance and disclose their child’s mental health problem to selected people… not everyone, but a few. These people are taking a risk, however, as these people may tell others. Also, others may find out and may shun them. For example, some parents say that *“my family think that it’s a load of rubbish*”, *“especially with grandma and medication.”*

With this risk comes opportunity. Parents who disclose may find people who are supportive. For example, one mum said, “*Now that I told Mary about my daughter’s ADHD, I can talk to her about the side effects of the medication.”* You also won't have to worry about keeping a secret from those to whom you've disclosed*.* You can keep the challenges private from those you don’t want to know, but not others. As one parent commented, *“We definitely do selective disclosure. We can’t tell our daughter’s friends because then they can’t come to play because of stigma.”*

1. ***Indiscriminant Disclosure***

People who choose indiscriminant disclosure choose to disregard the potential negatives of people finding out about their child’s challenges. For example, one parent commented, *“I sometimes feel that I owe it to my kids to be an advocate for them… so I’m an over-sharer.”*

This is not the same as talking with everyone. Not keeping a secret means that you are no longer trying to hide it.

If you choose indiscriminant disclosure, not everyone will respond to your message well. The difference is that you no longer worry about hiding your child’s symptoms or diagnosis. You are saying, *“take me and my child as we are.”*

Taking this path requires a hardy personality. Some will react negatively; they might say *“There’s no such thing as ADHD – it’s just lazy parents wanting to medicate their kids.”* So, you need to be able to cope with this disapproval and consider how this will affect your child now and in the future. One way to tell whether or not you are up to this is to role-play these types of situations (which we will do next)*.*

1. ***Broadcast Your Experience***

Indiscriminant disclosure means no longer trying to hide your child’s challenges. On the other hand, you are not likely to go out of your way to inform people about it. Broadcasting your child’s challenges means educating people about them. Your goal is to seek out many people with whom to share your and your child’s history and current experiences with mental health challenges.

Broadcasting your experience has the same benefits as indiscriminant disclosure. You no longer need to worry about keeping a secret. You will also find people who may provide understanding, support, and assistance.

However, even though it risks encountering stigma more often, people who choose to broadcast their experience seem to derive an additional benefit: it seems to foster their sense of power over stigma. They reject others’ opinions that they or their child might be inferior in some way.

*“My kid is equal to everyone else. I have nothing to hide.”*

*“Everyone gets an overview these days. Not much, but then if they really need to know more, I tell them.”*

Broadcasting your experiences can be met with more than just hostile responses (as in the case of indiscriminant disclosure). Broadcasters can also get angry responses to the message. You also need to consider how your child will feel about you telling others openly.

**Do participants need more time to go through their own list of pros & cons? Give them some time if they do, and you can ask them to volunteer what the most influential things were for their decision.**

The main point here is to recognize that there are advantages and disadvantages of each decision, and that everyone has the right to choose their own approach as to what will work best for them considering their child, self, and situation.

### Task 2. How Might Others React?

LEARNING OBJECTIVES

* Disclosure will impact you, your child, and others around you.
* Others may react in very different ways.
* These reactions might surprise you. Take time to consider the different ways that people will react.

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| **IN THE WORKBOOK:**  ***Table 2.2* (p. 30)*, “How People Might Respond”* lists a variety of reactions to disclosure that are grouped by positive versus negative emotional response.**  ***Worksheet 2.2* (p. 32), *“Your Reactions when Others’ Respond Negatively”* provides a format for role-playing people’s negative reactions to your disclosure as well a place to rate your feelings in response to these statements.** |

If you decide to talk about your child’s challenges, this will impact the people around you. Whether you choose selective disclosure or broadcasting, those who hear what you have to say are likely to react, and some of these reactions might be surprising. You need to consider the different ways people may respond, and accept what your reactions will be.

Some people can react positively – with warmth, understanding, and/or offers of help. Others, though, can react negatively… disrespectfully, with fear, or with denial. Some of these reactions may affect you, some your child, and some may affect both. When you are met with these negative reactions, you might feel shocked and forget what you were going to say, or be too surprised to think clearly, especially when someone you thought would be supportive isn’t – like, “*Back in the day they would’ve gotten a good smack.”* As one parent said, “*You can practice but as soon as one person says it’s all rubbish, you forget everything”* and a mother said, “*I have brilliant comebacks… 30 minutes later.”* Even so, preparing yourself now may be helpful because, as other parents have commented, when you talk about your child’s challenges, “*you are very vulnerable.”* Parents have said that preparing for this would make them *“feel more empowered.”*

So, take time to look at *Table 2.2*. There are a variety of reactions to disclosure, which are sorted into groups based on whether the reaction is positive or negative.

Are there other examples missed here?

***\*Ask participants what they might add that is missed, or what stands out the most for them before moving on.***

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| ***Table 2.2: How People Might Respond*** | |
| **Positive** | **Negative** |
| **Understanding**  *“It must be hard living with your child’s challenges and feeling like you can’t talk about it.”*  **Interpersonal Support**  *“I’m here for you if you need someone to talk* *to.”*  **Assistance**  *“Can I pick up your elder child after school if you need to go to the doc?”* | **Disrespect to you**  *“I just don’t think that medication should be given to kids.”*  **Denial**  *“There’s no such thing as ADHD.”*  **Retribution towards your child**  *“I’ll make sure your kid doesn’t get invited to birthday parties.”*  **Fear/Avoidance of you or your family**  *“Your kid is dangerous. I need to keep my kids away from her.”*  **Gossip about your child**  *“Hey, did you hear about John? He was just diagnosed with ‘bipolar’.”*  **Blaming you**  *“The apple doesn’t fall far from the tree.”* |

**How will YOU respond?**

Let’s get a feeling for how you will respond emotionally to negative, hurtful feedback. *Worksheet 2.2* on the next page gives you a chance to try out how it might feel to talk about your child’s challenges. Find a partner and role-play talking about your child’s challenges. Say something that you would like to tell a parent of your child’s friend. The example in *Worksheet 2.2* is “*My child was diagnosed with ADHD and depression late last year.”* Then ask your partner to say response 1: *“What is your child doing in this school?”* Pause a few seconds and repeat your comment. “*My child was diagnosed with ADHD and depression late last year.”* Ask partner to say response 2. Continue in this way.

The goal of this exercise is not to practice what you will say, or what you will do. The goal is to get a sense of how you feel when someone you talk to responds harshly. Once you’ve finished, complete the four items below the box. Scores above a 4 on any scale in *Worksheet 2.2* suggest that these kinds of insults may hurt you. This is understandable. You are reporting significant feelings of shame, anxiety, sadness, or anger because of hurtful comments. You need to ask yourself whether or not you want to put up with this kind of grief. And, remember, a comment from a partner in a role-play has far less sting than one from a co-worker or friend in real life.

***After participants have some time to practice Worksheet 2.2, move on to:***

### Task 3. Developing Your Coping Plan

LEARNING OBJECTIVES

* + Not everyone you talk with will be supportive
  + Decide on what you would like to say or do when someone you talk with reacts negatively.

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| **IN THE WORKBOOK:**  ***Worksheet 2.3* (p. 34)*, “Coping with Others’ Negative Responses”* provides participants with the opportunity to think about how they will deal when they are faced with someone who reacts negatively to their disclosure** |

### OK, now you have had time to think about your reactions to a number of hurtful remarks that others might make. It’s hard to plan what you would like to say to all of these negative reactions and then to remember them and say them when you need to. You may wish to try this, though. Another option is to develop a coping plan: this is a plan of what to do after talking with someone has resulted in a negative reaction. Developing a coping plan might be a good way to prepare yourself for these times. A coping plan is a set of strategies to help you deal with something that is emotionally hurtful or upsetting. The idea is to help you reduce your stress or hurt feelings.

### Take a look now at *Worksheet 2.3, ‘Coping with Others’ Negative Responses.’* This asks you about positive ways that you could think or talk to yourself. It also asks you to think of someone you can talk to who you know will be supportive. There might be other ways you like to cope, like preparing yourself to leave from the conversation you are having calmly by counting backwards from 10, or simply saying something that is important to you (like, ‘I’m surprised to hear you say that, I had been expecting a different reaction’) each time before excusing yourself to leave the conversation. If there is anything else, add it to *Worksheet 2.3*. You may wish to refer back to this worksheet if you need it in the future. Take some time now to do this worksheet.

**HOMEWORK**

***At the end of the lesson time, say***

### OK, so you can keep on changing this, and refer back to it if you need it now or in the future.

For Homework, continue to think about your reactions. It really is hard to plan what you would like to say to all of these negative reactions, and then to remember them and say them when you need to. So, keep on working on your coping plan. Make sure you complete *Worksheet 2.3* before the next session. Next week we’ll talk about how to discuss your child’s challenges if and when you decide to – that includes who you’d like to tell what to and how.

# LESSON 3

## Telling Your Story

LESSON OVERVIEW

As a result of Lessons 1 and 2, you might have decided that you want to talk to others about your child’s challenges now, or perhaps in the future.

This last lesson before we take a break has several goals.

Task 1 How to decide *what* you would like to say

Task 2 Deciding *how* you would like to tell it

Task 3 Practice trying it out. How did it go?

Task 4 Putting it all together

Task 5 Looking forward

### Task 1. What would you like to say?

### Disclosing from a position of strength

LEARNING OBJECTIVES

* Sort through your ideas on what you would like to say
* Decide on what you would like to.

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| **IN THE WORKBOOK:**  ***Worksheet 3.1* (p. 38), *“How to Talk about my Child’s Challenges”* gives participants the opportunity to think about what they would like to say about their child’s challenges** |

**Here, you guide participants through deciding *what* participants would like to say to others. Some might have decided not to tell anyone; if that’s the case, then they can try thinking this through in the case that this changes for them in the future. Others might have already disclosed a lot; they can decide how what they usually say is meeting their needs, and their child’s needs, and presents their child from a position of strength. Note that partners (e.g., husband and wife) might disagree on what they would like to say; this is fine as it is a personal decision and so they should think about making up their own minds about disclosure and respecting that it is a personal decision based on what they each think is best for their child. Below is what you can say to lead participants through these decisions.**

Just because you have decided to talk about your child’s challenges does *not* mean that you have to disclose everything. Here we will talk about things to keep in mind in order to make your own decisions about what you would like to talk about.

Four keys to ask yourself in deciding:

1. Will this help (or hurt) my child?
2. Will this help (or hurt) me and/or others I care about?
3. Have I included everything that I want to, including what is relevant?
4. Have I presented myself and my child with dignity?

**1. Will this help (or hurt) my child?**

Parents think first and foremost about **what is in the best interests of their child.** This means that you should think of what you say in terms of whether it will help your child, hurt your child, or neither. Some things might do both, and you will need to balance the potential for benefits vs. costs. For example, talking with your child’s teacher at school may cause potential harm (e.g., you may wonder, *“What if she sees my kid more negatively now?”*) but also potential help (e.g., your child may be disadvantaged if the teacher does not know about the problem and some effective things to do). You need to weigh these up.

**2. Will this help (or hurt) me and/or others I care about?**

Similar to the first key, parents also need to think about themselves and others they care about (partner, other children). Will your disclosure to your child’s teacher or childcare/daycare provider, for example, have a positive or negative impact on other children you might have? You need to weigh these up as well.

**3. Have I included everything that I want to, including what is relevant?**

You don’t have to disclose everything… but be sure to sift through what you want to say and discard that which you don’t. What you tell your child’s teacher might be different than what you tell your closest friend. Be sure to include what is relevant to each person… so you need to think about your goals. For example, what your teacher needs to know in order to help your child learn is different from what your closest friend needs to know in order to be supportive and helpful.

Each family has a different story to tell, and it is okay if this differs for the people you tell. We think that it is important to include information about how you and/or your child have struggled, and also about how you and/or your child have hope and/or accomplishments you have achieved.

**4. Have I presented myself and my child with dignity?**

Telling your and your child’s story with dignity means that you are neither painting an overly bleak and negative picture, nor are you presenting it in an overly positive way (‘with icing sugar on top’). Remember that your child’s challenges are just *part* of your child, *not all* of your child. Having an anxiety disorder, for example, is one of many aspects to your child. As a parent, helping your child cope with anxiety is just one aspect of your parenting. This will help the person you are telling to see your child, and not just your child’s challenges, as well as you as a parent, and not just as a parent of a child with challenges.

Now take a look at *Worksheet 3.1* (p. 39), and give it a try for one person you’d like to talk with from back in the first meeting when you did *Worksheet 1.3*. If you have not decided or decided not to disclose, then choose someone you might think about in the future. If you have already disclosed, then you could think about a challenge you have not disclosed, or someone you have already disclosed to and see if you are satisfied with what you’ve said or would like to add or clarify something.

This could be easy for you, or it might take some time. Don’t do the very last question on the worksheet – we’ll work our way through just *how* you’d like to disclose shortly. Start this worksheet by thinking of someone you have decided to talk to about your child’s challenges, and place his/her name at the top. Now, take some time to think about what you would like to say with these things in mind.

***Allow participants time to go through the worksheet.***

**Task 2. How would you like to Disclose?**

LEARNING OBJECTIVES

* Think about the many different ways you could talk to others about your child’s mental health challenges.
* Select how you would like to disclose.

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| **IN THE WORKBOOK:**  ***Worksheet 3.2* (p. 48)*, “How to disclose?”* helps you to identify different ways to disclose and weigh up the pros and cons of each*.*** |

There are many different ways to disclose information:

* In person
* By phone
* Through writing – an email or letter

You can even mix some of these together – for example, you could follow up an email with an in-person visit; or you could bring a point-form list of what you would like to say with you when you tell someone in person. How do *you* feel best about letting this other person know about the challenges your child has been having?

Look at *Worksheet 3.2* and think about the pros and cons of each method. Is there another method you would like to consider? After you have finished this, go back to *Worksheet 3.1* (bottom of the previous page) now and think about how you would like to relate your story. Write your answer. You might decide on different ways of telling different people – that’s okay.

**Remember to remind participants to go back to *Worksheet 3.1* now and think about how they would like to relate their story.**

**Task 3. TRY IT OUT**

LEARNING OBJECTIVES

* Writing your own story

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| **IN THE WORKBOOK:**  ***Worksheet 3.3* (p. 51), *“How it went”* provides an opportunity to rate the quality of your experience in disclosing your child’s challenges.** |

**Now is time for participants to begin to develop their story. Make sure that participants know that this might only be the start of developing and practicing their story, and that they may continue this at their own pace.**

Developing your story on your own and then sharing it with another person are two very different experiences.

Now is an opportunity to find a partner and relate what you would like to say to him/her. So – **get out *Worksheet 3.1* and use this as a guide to help you tell your story.**

Before you do this, let your partner know who the information is intended for (e.g., your close friend, your child’s teacher or childcare providers, etc.). Now tell this person about how you will relate this information (e.g., in person/by telling them, in writing) and take 5 minutes for you both to practice (e.g., practice saying the information, or trying writing it out). Because writing can take a long time, try point form, or perhaps start with someone you have decided to tell in person as your first practice.

Then relate the information in the way you chose (e.g., in writing or in person). When done, complete *Worksheet 3.3*, *‘How it Went.’* Try to write anything in the box not captured in the four questions. When done, listen to your partner’s story. 30 minutes before the group ends, we’ll join as a group and share the experience.

### Task 4. Putting it All Together

LEARNING OBJECTIVES

* Summarize insights from the worksheets provided in this workbook.

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| **IN THE WORKBOOK:**  ***Worksheet 3.4* (p. 53), *“Wrapping it All Up”* provides discussion questions to encourage reflection on what you have learned from the program.** |

We end the program with a pause for reflection. In *Worksheet 3.4*, questions are provided so that you can summarize your insights and decide on future directions. Complete these and then share your responses with a partner. After finishing your discussion with a partner, come back to the group as a whole and discuss one or two decisions that you have made about going forward.

***Note: Take these questions up as a group. Allow 10 minutes for this task.***

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| ***Table 3.4: Summary of Reflection Questions in Worksheet 3.4 – “Wrapping it All Up”. Take this up as a group*** |
| * What did you learn about stigma and disclosure from this program? * What are the main costs and benefits of talking about your child’s challenges? Are you planning on talking about your child’s challenges to others? (*Worksheet 1.3*) * What ways might work best for you in terms of disclosing? (*Worksheet 2.1*) * How did you feel about stigmatizing responses from others? (*Worksheet 2.2*) * How confident do you feel in using your coping plan, and what strategies do you think will be most helpful? *(Worksheet 2.3)* * What do you think of developing your story before you disclose? (*Worksheets 3.1* and *3.2*) |

### Task 5. Looking Ahead

LEARNING OBJECTIVES

* Decide how you would like to move forward.

## You’ve had a lot to think about, and some time to reflect. Now, think about how you would like to move forward. We’ll meet again in about 1 month’s time. Is there anyone you would like to talk with in that time? Perhaps you will wait longer than that? Is there anything you need to do before that happens? Look at *Worksheet 3.5, “Looking Ahead.”*. Complete these for homework.

## You also can work more on *Worksheet 3.1, “Telling Your Story”.* You might want to change things from today’s practice, or work on what you might say to someone else.

## Remember to bring your Workbook copies with you, and we’ll see you again in 4 weeks – that will be:

## Have everyone write down the date of the next meeting now.

## Before everyone leaves, ask them to complete the ‘Post’ Measures.

## FINAL SESSION

## 1 month later

FOLLOW-UP OVERVIEW

Talking to others about a child’s mental health challenges is the right decision for some, but not for everyone. We’re meeting today to review your decisions since we last met about one month ago. We approach this follow-up in two parts:

1. We review who, if anyone, you intended to talk with at the end of the group sessions. We will then discuss who you have talked with so far, and what your experience was. If you have not started these conversations with others, you can talk with those who did about their experiences.
2. Peer support. We discuss the possible role of peer support in your future.

**Task 1. Who did you intend to talk with, and who have you talked with?**

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| **IN THE WORKBOOK:**  ***Worksheets 1.3 & 3.5* (p. 56) was where participants made decisions about their intentions to disclose with others.**  ***Worksheet 4.1* (p. 58), *“Who did you want to talk with? Have you at this point”* allows participants to review and think about their experiences in disclosing.** |

Over a month ago, you worked through costs and benefits of having conversations with others about your child’s mental health challenges. Find your copies of *Worksheet 1.3, “The costs and benefits of talking with others about my child’s challenges.”* Who, if anyone, did you decide to talk with? Write this down on the next page. In the next column, place a check if you have now started these conversations.

**Give participants time to do this.**

*Final Session Worksheet 4.1*

**Who did you want to talk with? Have you at this point?**

When you completed the *Starting the Conversation* baseline program about one month ago, did you intend to disclose?

Yes No

If yes, please fill out this table.

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| --- | --- |
| **Who did you decide to** **disclose to** (*from Worksheet 1.3)***?** | **Have you talked with this person?** |
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**If no, why did you decide against it?**

**How Did It Go?**

FOLLOW-UP OBJECTIVES:

* If you have had these conversations, describe how it went.
* Explain how the experience changed/didn’t change your mind about disclosing.

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| **IN THE WORKBOOK:**  ***Final Session Worksheet 4.2* (p. 60), *“How Did It Go?”* provides a format for evaluating a specific act of disclosure and gives participants space to discuss whether the experience has changed their mind about disclosing in the future.** |

You may have talked with others since we last met. If so, reflect on how it went here. If not, you can learn from others’ experiences.

Look at *Final Session Worksheet 4.2*. First indicate to whom you disclosed and the location. This will help track things that make it more or less likely that the conversations are helpful, and for you to develop strategies for talking with others in the future. Then, consider what your goals were for disclosing to this person and note what you said. Next, write down how the person reacted. It might also be important for you to note the tone of their voice and their body language, especially if it does not seem to match what they said. Finally, rate how satisfied you were with the conversation and how well it went.

**When everyone is finished, have those who actually disclosed pair up with a participant who did not so that they can share their thoughts. Participants who did not disclose should use this opportunity to understand what disclosure might mean for them in the future.**

*Final Session Worksheet 4.2*

**How Did it Go?**

Fill out this page if you have started a conversation with someone this past month.

Name of the person:

Date of the conversation: Place:

Your Goal(s):

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What you said

Person’s Reaction

How satisfied were you with the exchange?

How positive was the exchange?

Thinking about how satisfied you were and how positive your conversation was, this may change your mind about talking with others in the future. Has it? If so, *how? Is there something you would do differently?*

**Task 2. Where to find support?**

FOLLOW-UP OBJECTIVES:

* Discuss what peer support means to you.
* Identify pros and cons of peer support programs.
* Evaluate what role you would like peer support to play in your life.

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| **IN THE WORKBOOK:**  ***Final Session Worksheet 4.3* (p. 62), *“Peer Support”* helps participants to list the pros and cons of peer support and the role of peer support in their future.** |

Social support helps in many ways. It helps us to air our frustrations, gives us someone to celebrate our successes, and can provide us with help when we need it. By being with other parents of children with mental health challenges in this program, you have experienced “peer support.” This support does not have to end here – you can continue to seek peer support in a variety of ways.

Here are some examples that parents have thought of:

* Join an established peer support group for parents of children with similar challenges (e.g., ADHD support group)
* Seek further peer support from other parents in this current group (e.g., by meeting together once a month, organising family picnics at a park, sharing phone numbers, or establishing a “closed” online social support group such as through Facebook).

**As the facilitator, you can now work with the whole group to get ideas about the pros and cons of each type of peer support that parents could access or develop. If applicable, try to establish what is needed to begin this support. The remainder of the session can be spent on this task, general social support, and completing ‘follow up’ measures.**

**Appendix 1. Challenging Personally Hurtful Self-Stigma**

**This appendix is included for parents who feel that they are harshly judging themselves – that they are agreeing with the negative judgments or stigma that they are encountering. If they do not wish to complete this section, they can leave it blank. Here there is a copy of this appendix included in case any participant asks about it.**

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| LEARNING OBJECTIVES   * Some parents internalize stigma and feel shame as a result. * This lesson teaches ways to manage thoughts related to self-stigma. |

Now let’s challenge the assumption: that *it is shameful to have a child with depression*. To do this, we will use an example from a father, Alan, to see the process he went through.

Alan believed that mental health challenges in a child meant that parents should be ashamed. By completing the worksheet, he looked at the assumptions he was making by changing the statement from a personal *“I”* belief, to a statement that includes *“all people like me.”*

Here is what Alan thought of:

* *All parents of children with depression are shameful.*
* *Depression in a child is something that brings shame to the parents.*

The truth of *“I”* statements is not always clear; however, change it to a general statement about everyone, and its falseness becomes evident.

Alan decided to challenge these assumptions by asking others whether or not they believe the two attitudes are true. Alan sought out some close trusted friends and his sister. He has confidence in all of these people. Alan was surprised by their responses. Not only did they disagree with the statement that *“All parents of a child with depression are shameful,”* but they all shared some experiences they have had with their own children struggling with depression or anxiety. Alan was especially moved by what Connie said, *“No way, Alan. Things happen… every parent knows that. Being a parent is hard enough, being a parent of a child with depression even harder. What you do for her is impressive, not shameful*

**Here is Alan’s completed worksheet.**

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| ***Table A.1: Change Our Attitudes Exercise ALAN*** |
| **1. State the hurtful belief.**  I MUST BE ashamed BECAUSE I have a child with depression. |
| **2. What are your assumptions? Use ‘all people like me’ statements:**  All parents of children with depression are shameful. |
| 1. **Challenge the assumptions by checking them out with whom?**    * I’ll ask my closest friend, Matt. And I’ll ask Mark and Harry at work. They’ll be up front. They have kids.    * My older sister. She is smart and always tells me the truth. |
| 1. **Collect evidence that challenge the assumptions.**    * My friends say that challenges in kids, like mild depression or anxiety, happen a lot, and they don’t feel ashamed when it happens to them.  * My sister said that dealing with my child’s depression is impressive, not something to feel ashamed of. |
| **5. Restate the attitude so that it doesn’t hurt you. This is a COUNTER.**  I’m not ashamed because my child has depression.  In fact, I deal with what other parents do, and then some. I should feel proud. |

Not only was Connie's feedback supportive, but it countered his belief about feeling ashamed as a parent.

As the final step, Alan translated his findings from *Table A.1* into a **counter.** Even though Alan benefitted greatly from feedback from his friends and sister, he might struggle with these beliefs again. Alan put the various things people said about not being ashamed together into a counter statement that he could use in the future against that belief, and wrote this in a private section of his day-timer/organizer so that he could read it when he is struggling.

*“I’m not ashamed because my child has depression. In fact, I deal with what other parents do, and then some. I should feel proud.”*

Let’s use *Worksheet A.1* on the next page to change a hurtful attitude you hold about your experience with your child’s challenges.

What are some of these hurtful attitudes? Find them from p. 11 (Lesson 1).

*Worksheet A.1*

**Change Our Attitudes Exercise**

Complete all five steps.

1. **State the hurtful belief (*find from p. 11)*:**

I MUST BE BECAUSE .

1. **Define the True-False Assumptions:**
2. **Challenge the assumptions by checking them out with whom?**
3. **Collect evidence against the assumptions:**
4. **Restate the attitude so that it does not injure you. This is a COUNTER.**

*Worksheet A.1*

**Change Our Attitudes Exercise**

Complete all five steps.

1. **State the hurtful belief (*find from p. 11)*:**

I MUST BE BECAUSE .

1. **Define the True-False Assumptions:**
2. **Challenge the assumptions by checking them out with whom?**
3. **Collect evidence against the assumptions:**
4. **Restate the attitude so that it does not injure you. This is a COUNTER.**