COLLABORATION IN PATIENT PATHWAYS

advice to Children and Adolescent's Psychiatric Outpatient Services

CHANGE FACTORY

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The photos are of participants from the advice collection

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ABOUT THE ADVICE COLLECTION

The Norwegian Directorate of Health is developing patient pathways for mental health further in 2023. This can be of great importance for children who go to Children and Adolescents' Psychiatric Outpatient Services (BUP). In order to contribute to the knowledge base to further develop this scheme, Changefactory has collected advice on how children can be met wisely from start to finish in mental health care for children and young people.

In the advice collection COLLABORATION IN PATIENT PATHWAYS, advice from 42 young people aged 13-21, are presented. The advice has been collected in 2021 - 2022.

Participants and collecting advice

The young people who have given advice, all have experience from BUP. The young people lived in Vestland, Viken, Nordland, Innlandet, Trøndelag, Møre og Romsdal, Vestfold og Telemark, Oslo, Agder, Troms og Finnmark, and Rogaland. They are "pros" in Changefactory.

The advice was given in one-on-one conversations, group dialogues and creative assignments. The UN Convention on the Rights of the Child defines everyone up to the age of 18 as children. This includes all children, including younger children and children who are perceived as sick or difficult. In this booklet, the word child is mainly used because the advice is about services for those under the age of 18.

Themes in the advice collection

The young people were asked to give advice on

- referral and assessment conversation
- first conversation in BUP
- treatment in BUP
- evaluation and finishing BUP

In the advice collection, there were no questions about the contents of the treatment in BUP, but about the surrounding framework. Advice from children and young people about the contents of treatment, can be found in the book "MENTAL HEALTH CARE, FROM US SOM KNOW IT" (Universitetsforlaget 2019).

Information and consent

The young people have given their consent to give advice. If a young person is under the age of 16, their legal guardian also has to consent. Separate consent forms for participation in photos are collected from the young person and their legal guardian if the young person is under 16 years old.

Before the young people give advice, they are given information about the topic they will be working on, why the advice about this topic is being collected, and what the answers will be used for. They are also given information about that they only participate in what they themselves want to, and that their participation is anonymous.

About the method

The advice collection was conducted using the Changemethod. This is a participatory research method used to gather in-depth knowledge for use in change work and equal collaboration with those who participate. It is developed based on Participatory Learning and Action (PLA), and further developed in collaboration with children and young people, to ensure that participation in a qualitative survey can be arranged in a safe way.

The Changemethod consists of a set of core values, working principles, and a number of specific tools to collect experiences and advice directly from children and young people. The tools are creative and visual, aiming to make it safe, fun and helpful for a wide range of children and young people.

Summarising the knowledge

The advice collected was sorted thematically. The answers that were repeated most often by the young people are summarised here as knowledge from children and young people. The language used is as similar as possible to the language the young people have used.The knowledge from children and young people is not connected to theory or analysed.

THANK YOU TO THE PROS
A MILLION THANKS TO EACH AND EVERY ONE OF YOU WHO HAVE HELPED GIVE IMPORTANT ADVICE. WE ARE VERY GRATEFUL THAT YOU HAVE HELPED NORWAY BY GIVING ADVICE ON HOW TO MEET CHILDREN IN BUP IN THE SAFEST AND MOST HELPFUL WAYS POSSIBLE. NOW WE HOPE THAT POLITICIANS, THOSE WHO WORK IN THE SERVICES AND STUDENTS TAKE THIS ADVICE VERY SERIOUSLY <3

ADVICE

KNOWLEDGE
FROM CHILDREN
AND YOUNG PEOPLE

KNOWLEDGE FROM CHILDREN AND YOUNG PEOPLE

This section presents what Changefactory calls summarised advice from children and young people. 42 young people aged 13 to 21 have participated in the advice collection. All the young people who have participated have experience with BUP.

Themes in this section:

- Safety
- Referral
- First conversation
- Important to the child
- Deciding the help
- Evaluating the help
- Finishing BUP

The UN Convention on the Rights of the Child defines everyone up to the age of 18 as a child. This includes all children, including younger children and children who are perceived as sick or difficult.

In this booklet, the word child is mainly used as the advice relates to services for those under the age of 18.

FOR SAFETY

In the book MENTAL HEALTH CARE, FROM US WHO KNOW IT, there are many answers from children and young people about what can make it safe to be in BUP. The young people in this advice collection were not asked this question. However, advice related to safety has been repeated and is therefore presented here.

Get to know each other

In order to open up and share, children must feel safe enough with their therapists. If children are going to share from their lives, they need to know a bit about the person they are talking to. Therefore, therapists have to spend time getting to know the child, not just in the first meeting. Without the therapists having put in enough time for them to get to know each other, it can be difficult for them to provide good help.

Consider contact with caregivers

Therapists cannot know what kind of relationship the child has with their caregivers. Each time therapists are going to bring caregivers into an appointment, children ask that therapists, as far as possible, check with the child first. Without this, children can lose trust.
If children lose trust, it can make it difficult for them to tell, and accept help.

Explain tests and forms

Being asked to fill out a form can feel very impersonal, and that can make it difficult to give good answers to what is painful or difficult. When a child is asked to take a test, they might feel that their emotions are not taken seriously. With these experiences in their body, it may take longer for the child to be able to share. For many children, tests and forms can contribute to making BUP feel unsafe.

If children have to be tested and/or fill in a form, they have to be explained exactly why. They need to know why this has to be done, who will get to know what the child answers, and who the child can ask if there is something they do not understand. The child can, if this is possible, choose if they want to fill in the form together with their therapist, or at home.

QUOTES:

It's their [children's] life and they [therapists] can never know whether it's safe if the parents find out, and that they [parents] can be good, but like with me they are good. But I want them[parents] to know at my own pace.

In order for me to talk about it, it's important that the psychologist gives a bit of themself, because then it's more open for me to give a bit of myself, and because I feel that it's good to say things directly instead of beating around the bush

Make it so that the child can choose whether they want to bring their parents or not. That's mainly it, that it should be safe and that the child should know who they're talking to.

REFERRAL

When a child is going to be referred to BUP, the main answer is that general practitioners (GP), as far as possible, write in collaboration with the child. When BUP receives a referral, it has to be taken seriously. Every child should, as far as possible, get to talk to someone about the referral, to find out whether BUP is the right place to get help or whether BUP should refer the child somewhere else. This conversation does not necessarily need to take place at BUP.

When GPs send a referral

Say what BUP is and can help with

- then children will know what they might be getting into
- then they can think about what kind of help they might need
- it can make it safer for children to go to BUP

Say why you are thinking of sending a referral

- then children can understand that it is to help them
- then children can explain what they think about it

Say who will get to read the referral

- then children can feel that they have some control
- then they can maybe tell what is painful or difficult

Say what happens after a referral is sent

- then children can feel that they have some control
- then they know better what can happen

Ask children to write together

- then children can choose whether they want to write together or not
- it can make it safer for the child
- then they can help decide what should be written
- then you can include what children think and feel in the referral

Ask children what should be written

- then you include the child's thoughts
- then the referral can be more accurate
- then it can be more helpful when the child comes to BUP

Listen to what children say and take it seriously

- because children know best what it feels like to be them
- this can maintain trust in you and other adults

Check with the child at the end, before you send the referral

- you may have misunderstood something
- can make it safer for the child to come to BUP

When BUP receives a referral

People other than BUP can look at referrals

- there could be a separate office that looks at referrals
- different people can look at referrals, it does not have to be psychologists
- someone who knows a lot about what services are available for children can look at referrals

Bring everyone in for a conversation

- every child who is referred to BUP must be able to speak to an adult about the referral
- every child must not have to wait long, otherwise, it can become worse
- every child has to experience that the referral is taken very seriously
- every child has to be asked what is important for them to get help with

Make it safe in the assessment conversation

- say that the child can bring a person they feel safe with
- ask the child what they find difficult and need help with
- give the child information about what help is available, in addition to BUP
- find out together with the child whether BUP is the right place
- talk about what is written in the referral to avoid misunderstandings
- find out together with the child what the best thing to do going forward is

Every child who needs help has to get help in BUP or somewhere elsewhere.

QUOTES:

If you're a GP, I'm supposed to just see you for 5 minutes and then you write the referral and tell something about me to BUP. Should this really determine my life, whether I get better or worse?

If the psychologist receives the letter, it isn't certain that it's the same as what the child means. The child has to be allowed to read through.

Don't get a proper impression through a freaking letter. Then you can't hear it coming directly from the child's mouth, their body language and all that.

Don't say that "this isn't suitable for you", but rather have an alternative that fits. "This is right for you" or "we think this is suitable for you". Don't say "we can't help", rather "this can help".

Always have a meeting. Because you have to meet the child and see how they're doing. You won't get to know the child through writing. Therefore, there has to be a meeting to find out whether the child should get help or not.


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FIRST CONVERSATION

When it has been decided that children are going to go to BUP and they are going to their first conversation at BUP, children have to be given enough information about what help they can get and what could happen. When therapists meet children with warmth and spend time to get to know them, it can be crucial for whether they are able to tell.

When therapists show that they want to help and children know this, it will be easier to accept help and it can be safer to talk to them. When therapists spend most of their time in the first conversation getting to know the child, and not on forms, children can more easily start to open up about the things they struggle with inside.

If therapists are open and focus on the particular child they are talking to, it can be easier to find out how to help each individual child in the best way possible. If practitioners are honest about what they have read, children might begin to trust them.

Information

Before the first conversation, give children information about
- that the child can bring a person they feel safe with, if they want to
- what will happen with the things they tell and who else will get to know it

In the first conversation, give children information about
- what BUP is and what they can help with
- what confidentiality is and is not
- what the duty to report a concern means, so the child knows what can happen if they tell something serious
- that the child can ask to choose a therapist and change therapists, if they need to
- how BUP collaborates with other systems, so the child knows that this can happen
- what rights the child has in BUP

When children are given enough information
- the child can be able to share more
- the child can understand that the therapist wants to help and how they can help
- the child can change therapists, if that is what the child wanted
- the child can feel that it is safe to be there

Important that the therapist does

Ask children if they want to bring someone they feel safe with
- know that this can make it safer to talk to you
- ask the child about whether a carer or an adult the child feels safe with should be there
- assure the child that nothing will be shared with others without them knowing

Show that you want to help
- meet the child with a smile and warmth
- ask the child what can make it safe to talk
- ask the child what they think they need help with
- ask what the child expects from BUP

Get to know each other
- ask the child who they are and what they like to do
- tell a little about yourselves and what you like to do

Be open and focus on the child
- meet children as wise people
- try to find out how the child feels inside
- try to understand why the child behaves the way they do
- try not to form an opinion before you meet the child

Be honest

- tell honestly what you have read about the child
- ask the child in depth about what you have read

Listen and figure out the tempo together with children

- know that it may take some time before the child is able to open up
- ask the child how quickly they want to talk about what is difficult
- let the child finish speaking, without interruptions

Wait before you start with forms

- focus on getting to know each other in the first conversation
- know that forms can make it difficult and unsafe to be in BUP
- know that forms can lead to it taking longer before children are able to tell

QUOTES:

About confidentiality. Not many people know how far confidentiality goes. What is it that makes therapists breach confidentiality? Because what can happen is that they say "I'm not allowed to share information", and suddenly you come home to your parents, and just, shit, yes you have been told.

Then they have to talk to me and get to know the people I'm supposed to share everything with, my story. Difficult to be myself if I don't know the person I'm talking to.

Ask where the child wants the meetings to be. Not everyone likes meeting rooms, it may be that some people think football is fun, so maybe you have to meet there. Because it can make it easier for children to talk when they can do something they like.

FINDING OUT WHAT'S IMPORTANT

In BUP there can be a lot of focus on mapping and assessment. The main answers from children is that the goal of mapping has to be to find out what is painful or difficult inside the child, and what the child needs in order to feel better inside. To find out what each child needs, therapists have to ask what the child think is important to get help with.

Important that the therapist does

Ask what children need help with

- ask the child what is painful or difficult
- ask what the child thinks might help

Take children seriously

- take what the child says seriously, regardless of whether you think what they are saying seems insignificant
- ask follow-up questions to understand
- remember that you do not know what it is like to be exactly this child

Focus on the reasons why

- say that you understand that the child is feeling something painful or difficult
- ask what the child is feeling inside
- ask about the reasons behind the pain or difficulty inside the child
- explain that you are asking so you can help the child

”It has been set up as a standard approach. But to truly connect with people, you can’t treat everyone the same (...) it completely depends on who the person is.”

DECIDING THE HELP

To decide what kind of treatment or help a child should receive, each individual child has to be asked and collaborated with. The help can then become more helpful for the child, and the therapist and child can more easily find solutions together. A child can gain more trust in the therapist when they get to know what kinds of possibilities exist and that they can think solutions together with the therapist.

When creating a treatment plan, it is wise to make it in collaboration with the child. This way, the child can feel that it is their plan and that the plan can be helpful.

To decide what kind of help

Talk about opportunities
- explain what different treatments involve

Ask the child what they need help with
- ask the child what they think is most important to get help with
- take what the child says seriously

Give information about options
- suggest specific options
- ask the child what they think about the options
- if you have a suggestion, tell the child
- if the child does not agree, try to understand why
- explain why if something the child wants is not possible

Collaborate with the child
- if you disagree with each other, try to find a middle ground with the child
- find out together with the child what is best for that particular child
- focus on preserving the trust between you and the child

To decide the treatment plan

The treatment plan must contain

- what will happen going forward
- what help the child will receive
- who the child is going to talk to
- who the child can contact

Make the plan together

- talk to each individual child about what has to be included in the plan
- ask the child what they think is important to include in the plan
- talk together about what the child wants to be written down
- explain thoroughly to the child if there is something that cannot be written down
- make suggestions, but let the child choose their own goals

Use the plan along the way

- use the plan during the treatment
- remind the child regularly what the goal of the treatment is and check that the child agrees that this is the goal
- talk with the child during treatment about whether they think the treatment is helping
- change the plan if there is something that both of you think is not working

QUOTES:

One option doesn't always work for me even if it has worked for others with the same problem. That they do not determine one option. But come up with more options.

One of the first things to do is to approach the child and ask "what kind of treatment do you think will help you?". Believe that they can always put it into words and work from there. Based on their answers, the psychologist can use the expertise they have to find help. Start there.

The child has to be allowed to say it themselves. The psychologist can have as many goals as they want, but these aren't necessarily relevant to the child. Must be personalised for each one.

Incredibly lucky with my therapist. She is really understandable, she always tries to adapt things to me. And that's how I've had the opportunity to, if I don't want to sit in the office, we can go out and go for a walk, or sit in a cafe.

If they just decide that everyone should do this and that, and some children aren't comfortable with it, then they won't bother, or it becomes too complicated, and then they just answer "yes, it's going well" just to get it done with and then there might be something underlying.

I actually believe the most important thing about my therapist was that she listened to me. She could say what she thought, but that the most important thing was what I thought and felt. So important that the psychologist doesn't just talk about what she thinks is important and believes works. Becomes easy to go by the book, the template they have. But when I was allowed to share what I thought would work we managed to find something that worked for both of us.

EVALUATING THE HELP

To find out if the help is helpful for children, the child has to be asked along the way. How and how often you should ask, has to be decided with each individual child.

How the child is doing and how the treatment is going, can change quickly. It is not certain that a child will be able to answer honestly the first time you ask. Therefore, therapists have to ask regularly. When the child is asked regularly, they can feel whether they think it is getting better or not. When therapists ask, they have to show and say that they want to hear from the child. Then the can get honest answers and you can change the help if something is not working.

Important that the therapist does

Ask the child about

- how you can check with the child whether the help is working
- what the child thinks is good and whether there is anything the child thinks is not good with the help
- whether the help is working for the child
- the child wants to try something else or if anything needs to be changed

Show and say that you want to hear from children

- set aside time to hear from the child how they experience the help
- ask the child regularly
- ask openly, without having formed your own opinion in advance
- say that it is okay if something does not work for them
- say that you want to hear from the child
- show or explain to the child what you write down, ask if you have understood what the child has explained correctly

Take children seriously

- listen to what the child has to say and do not interrupt them
- do something about it, if the child says that something is not working

Give the option to answer anonymously

- give children the opportunity to give feedback about the treatment anonymously
- give the child the opportunity to tell someone other than their therapist
- know that in doing so, you ensure that as many children as possible have the opportunity to give feedback

QUOTES:

Things can go well, even if there are several things that could be improved. It would be so stupid to just ask if it's going well, because you won't get answers. Figuring out the difference between perfect, good, bad, what could be better, terrible and such. There are many things that are important to distinguish between.

If it's like, "I don't like my psychologist", "I don't like the treatment", "the treatment is really shit". Then they won't have to say it. Then they can say it anonymously. Or it won't be completely anonymous, but more than in real life, then it won't be so scary.

FINISHING BUP

When a child is going to finish BUP, it should not come suddenly. The child must be asked when they are ready to stop. Therapists have to figure out with each individual child about when this is, and gradually ease the process in a calm manner. This can make the transition to ending treatment feel safer, and the child does not have to feel like they are being thrown out.

When the decision to end treatment is made, it has to be a gradual process. Then the child gets to prepare themself. In the last appointment, it is important that it is nice, so children feel that helping the child meant something to the therapist and that they might have achieved something good together.

The child has to know where and how they can make contact if things become difficult again, after they have finished treatment. This can make it safer to end treatment at BUP.

To decide when

Ask about ending

- ask the child if they feel ready or need to be in BUP a little longer
- ask well in advance before you think the child should finish, so it is not sudden
- ask openly, so the child understands that they do not have to finish immediately

Decide together with the child

- find out together with the child when they should finish
- find out together with the child how finishing can happen, in the safest possible way for that child

Ending

Do it gradually

- make it possible for the child to reduce the frequency of coming to BUP, if that is what the child wants
- talk to the child about how the transition is going

Give information about help

- say who the child can contact if something becomes difficult
- talk about the kinds of help available in the area where the child lives

If the child is going to DPS (at 18 years old)

- write the referral together with the young person
- join the first meeting, if the young person wants it
- know that this can make being in DPS (Adult Psychiatric Outpatient Clinic) less scary

Nice final session

- do a nice activity, something good to eat or something else nice
- say and show that the child has achieved something good

Have a closing conversation

- talk to the child about what they have been through
- remind the child of the things you have worked on, learned and talked about
- make a plan in case something happens, so they can be somewhat prepared

After ending

- give the child the opportunity to make contact
- have a phone number or another way for the child to contact for help
- tell the child, if possible, that they can come to BUP again without having to go to the GP first

Follow up

- check on the child again after a short while, to see how they are doing
- let the child avoid going through the entire assessment process again, if they are having a hard time

QUOTES:

Will be a safer transition if I join in. If they're going to talk together without me, the transition will be like walking over an old rope bridge. But if I join in, it can be like an asphalt bridge.

It's about doing something nice in the last conversation. That can mean a little extra for children. Say you have the final outpatient meeting and an hour where we go for a walk or sit and drink hot cocoa and end on good terms.

NATIONAL SOLUTIONS

NATIONAL SOLUTIONS

Here is input to the national authorities, based on advice from the young people in this advice collection. The input is written by pros in collaboration with political advisers in Changefactory, with the wish to contribute to that help in mental health care has a good/ positive effect.

Children as a group have the right to be heard in further development of patient pathways

The Norwegian Directorate of Health is developing the patient pathways further. This can significantly impact the ways in which many children are sent to mental health care. According to the UN Convention on the Rights of the Child, children as a group have the right to be heard in this process.

The UN Committee on the Rights of the Child(CRC) writes:

> *"When the interests of a large number of children are at stake, Government institutions must find ways to hear the views of a representative sample of children and give due consideration to their opinions when planning measures or making legislative decisions which directly or indirectly concern the group in order to ensure that all categories of children are covered."* (General Comment No. 14, para. 91).

We hope that the Norwegian Directorate of Health takes this seriously, and includes experiences and advice from different groups of children in BUP, in the work to further develop patient pathways. We hope the advice in this advice collection will be included.

Children must be spoken to when referral is considered

In the commissioner's document for the Regional Health Trusts in 2023, the scheme of offering an assessment conversation to everyone who is referred to mental health health care for children and young people, is continued. This idea fits well with the main answers in this advice collection. The answers are clear about how each individual child must be spoken to directly, when referral is considered.

For children, this is important in order for the assessment conversation to be of good quality:

- the conversations should be held in the municipality, there is no need for it to be a specialist from BUP
- those who conduct assessment interviews must have a good overview of what mental health services are available
- the child must always be offered the opportunity to bring along a person they feel safe with
- the child has to be spoken to about the content of the referral
- the child has to know what BUP is and what they can help with
- the child has to be told which other mental health services are available, and what they can help with
- the child has to be asked which service they think it would be wise to get help from

Help regardless of diagnosis

In order for mental health services to have the opportunity to provide help that helps as many children as possible, children have to be able to get help in mental health care without being assigned a diagnosis. The answers in this advice collection have pointed out that to get help without a diagnosis is important. In the book "Mental health care, from us who know it", where 104 children and young people gave advice, a clear main answer was that children have to be able to receive help in mental health care, without a diagnosis being assigned. That the right to help in BUP is dependent on a diagnosis can make it difficult for therapists to reach into the pain or difficulty that children experience. If therapists have to set a diagnosis at the very beginning at BUP, children can feel that the therapists are concerned with the symptoms the child has, and not the cause of the symptoms. It can therefore stand in the way of the child getting the right help.

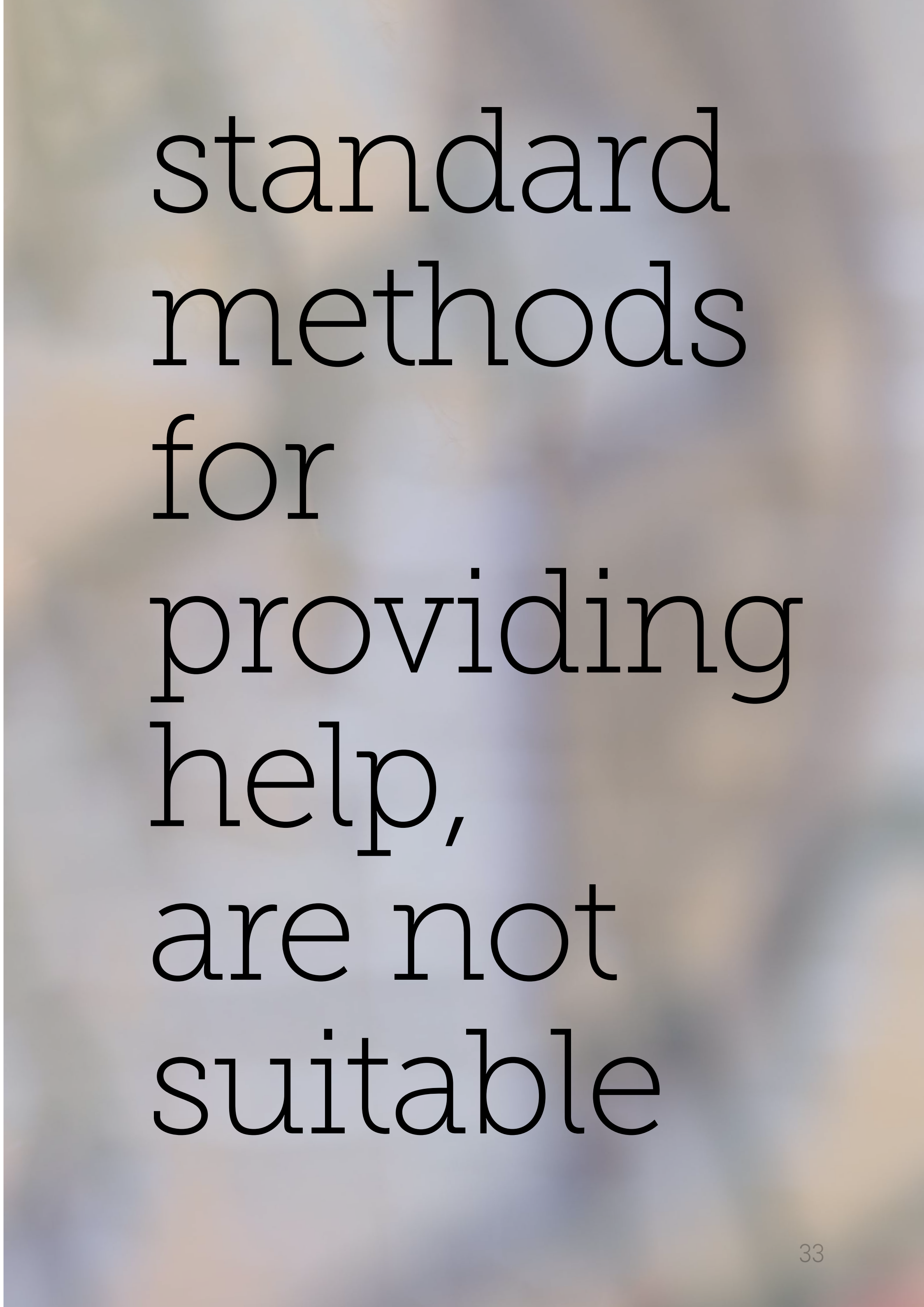
Help has to be determined individually

The young people who have participated in this advice collection have been clear that each individual child must be met based on what this exact child needs. Standard methods of providing assistance, therefore, are not suitable. Although different children might show the same expression of pain or stress, it can involve different things inside them, and they may need completely different help.

Each time when it is decided which help a child should receive, an assessment must be made of what is in the best interests of the child. This applies whether determining a diagnosis, medicine, involvement of legal guardians, treatment methods or who the child should talk to.

The UN Children's Committee on the Rights of the Child has stated that what is in the best interests of the child must be assessed concretely in each individual situation. In general comment no. 14, the committee specified that what is best for one child in one situation might not be the same as for all children in the same type of situation, but that each child is unique. An individual assessment should therefore be made (General comment no. 14, par. 48-49).

To help children based on standard methods or treatment plans does not, therefore, ensure the rights of each individual child, based on the main answers from children.



standard methods for providing help, are not suitable

CHILDREN HAVE RIGHTS

CHILDREN HAVE RIGHTS

The UN Convention on the Rights of the Child was made Norwegian law in 2003, through Section 2 of the Human Rights Act. The Convention on the Rights of the Child applies to all children under the age of 18. The Convention on the Rights of the Child must be used together with the special laws, and if the special laws say something different to the Convention on the Rights of the Child, the provision in the Convention on the Rights of the Child shall prevail. Some of the rights in the Convention on the Rights of the Child have been included in the various special laws, including section 104 of the Constitution in 2014, which is Norway's supreme law.

The Convention on the Rights of the Child and children's procedural rights

The Convention on the Rights of the Child gives children some procedural rights. These rights apply to all children in all systems. They describe how children should be met, in all actions and decisions that concern them, so that adults can assess what's in the best interests of the child. The procedural rights are the consideration of the best interests of the child, the right to information, the right to speak freely and the right to respect for their privacy.

Applies to all children in all meetings with health care personnel

Children's procedural rights must be ensured in all meetings children have with health care personnel. In a patient pathway, actions and decisions that affect children, can for example be situations where adults share information from or about the child with parents. It can be how much information the child receives, what treatment the child will receive and who the child will talk to.

The state has a duty to provide training

The authorities have a duty to ensure procedural rights for all children. The state therefore has a duty to ensure that the employees in the health services for children and young people know about children's procedural rights and know how to respect them and ensure them in practice (UNCRC art. 4). Children's procedural rights in accordance with the UN Convention on the Rights of the Child applies to all children who are patients - always. The rights apply regardless of whether children have consent competence according to the Patient and User Rights Act.

Children's procedural rights

The Convention on the Rights of the Child gives all children rights. The UN Committee on the Rights of the Child is responsible for the monitoring of states' implementation of the convention. The committee writes general comments (GC) to provide guidance and explanations on how the convention should be used in practice. In these, the committee underlines the connection between the rights and that they are interdependent.

In all actions and decisions affecting children, the best interests of the child shall be a fundamental consideration, (UNCRC art. 3). The child's opinion must be a central moment in the assessment of the best interests of the child.Furthermore, a prerequisite for the child to express themselves freely and safely, is that the child recieve enough information.

This means that an assessment can NOT be made in the best interests of the child without the child having first received sufficient and understandable information, and have been able to express their opinions freely and safely. The child's right to privacy must be ensured, by informing the child what information from the child can be used for and who can get access to this information, and that the child is allowed to express their view before it is decided that information will be be shared.

Children have the right to express themselves freely and to be cooperated with

-UNCRC art. 12, Norwegian Constitution art. 102 and pbrl. Section 3-1

Children have the right to express themselves freely in all matters that concern them, and their opinion must be emphasised. This is an independent right all children have, which neither parents nor other adults can limit.

As a starting point, the child's best interests cannot be used as justification so that children are not allowed to express themselves freely. To ensure children's right to express themselves freely in a patient pathway is an important part of ensuring collaboration with the child. Children have the right to information, to be heard and that their opinions should be emphasised (pbrl. Section 3-1.)

There is no age limit for when the child must be heard; the central point is whether children are able to express themselves freely about actions, decisions or questions concerning them. (GC no. 12 paragraph 20- 21).

Ensuring that children are allowed to express themselves freely is done by ensuring that:
- the child receives useful and understandable information (GC no. 12 para. 25)
- the child feels safe and respected (GC no. 12 para. 23)
- the child is allowed to express themselves without influence, pressure or manipulation (GC no. 12 para. 22)
- the child may speak without the consent of parents or others with parental responsibility

If other solutions are chosen than what the child wants, the child must be given the opportunity to express their views on how this solution will become. If it is considered that the child's statements should not be given any weight, it must be documented and justified which meaning and consequences that it may have for the child acting contrary to the child's statements.

Children have the right to information
-follows implicitly from BK art 12, cf. GK no. 12 sections 16, 25 and 41.

The UN Children's Committee states that children have the right to receive all the information necessary to be able to express themselves freely and help decide what is best for themselves in a situation. The right to information is therefore a prerequisite in order for children to speak freely about actions and decisions to be taken. Children's right to information, according to UNCRC, applies regardless of the special rules described below regarding the sharing of information to parents or guardians according to pbrl. § 3-4.

The right to information means that the child must, among other things, be informed about:
- the situation and the matter
- what information the adults have
- from whom they have received the information
- what happens with what the child tells
- which decisions can/must be taken further
- which alternative solutions exist
- what consequences the various choices may have

The information must be given in an understandable way, it must be repeated when the child needs it and the child must receive information along the way in the process.

Children's right to respect for their privacy
-UNCRC art. 16, Norwegian Constitution Section 102, Article 8 of the ECHR

The Convention on the Rights of the Child specifies that no child shall be subjected to arbitrary or illegal interference with their privacy. To safeguard children's rights to privacy is an important prerequisite for children's right to express themselves freely. The right to privacy applies to all children regardless of age and must be secured, as far as possible. Sharing of information from or about the child is an interference with the child's right to privacy.

Adults cannot automatically share information from or about the child with other adults, within a service, with other services or with parents. There must be an authority in law that allows sharing and it must be necessary to share this information.

The Patient and User Rights Act Section 3-4 third paragraph states that regardless of the patient's or user's age, information should not be given to the parents or to others who have parental responsibility, if weighty considerations of the patient or user speak against it. In the draft law it is stated that it is the assessment of what is in the best interest of the child that should be the primary consideration in the assessment. Therefore, the child must receive information that it is being considered to share information, and the child must be able to speak freely and safely about this action before information is shared. The child's own opinion must be a central element in the assessment of whether it is in the child's best interests to share the information.

Here it is particularly important to remember the starting point from the Convention, that all children have the right to respect for their privacy. Art. 16 and children's rights according to the UNCRC take precedence over the provisions in the patient and User Rights Act.

When considering sharing information:

- the child must know what can happen with information the child shares, at the start of the conversation
- adults must inform the child that sharing information is being considered and let the child express their views freely about this before the information is shared
- only the information that is necessary can be shared and sharing must not be arbitrary

In accordance with pbrl. Section 3-4, parents or others with parental responsibility shall be informed when the patient is under 16, and information that is necessary to fulfil parental responsibility must nevertheless be given to parents or others with parental responsibility when the patient is under 18 years of age. Professionals, services or health care personnel can share information from or about the child with others, but the procedure of giving the child information, letting the child express their views about the sharing and ensuring that sharing is in the best interest of the child, must first be followed.

Assessment of the best interests of the child
-UNCRC art. 3 and the Norwegian Constitution Section 104

The UN Convention on the Rights of the Child states that the best interests of the child shall be a fundamental consideration in all actions and decisions which concern a child.

The best interests of the child is an independent right and a procedural rule. This means that children have the right to have their best interests considered in all decisions that concern them and also that the best interests of the child must be considered and practised in all parts of a process that concerns the child. For example in patient pathways.

That the best interests of the child "shall" be a fundamental consideration means:

1. What is best for the child must be assessed in all cases and decisions made by health care personnel
2. Consideration of the best interests of the child must be given great weight and be the starting point for the decision (Rt 2015 p. 93 section 65)

What is best for the child must be decided on a concrete assessment where the child's own opinion is a central element (HR2021- 475-A section 62). The assessment must be done after the child has received information, given the opportunity to express their views freely and that the child's respect for privacy is ensured.

Facilitating the child's right to express themselves freely is central to the assessment of what is in the best interests of the child. If other solutions are chosen than what the child wants, the child must be given the opportunity to express their views on how this solution will become. If it is considered that the child's statements should not be given any weight, it must be documented and justified which meaning and consequences that it may have for the child acting contrary to the child's statements.

In order for actions and decisions in a patient process to be made in the best interests of the child, adults must ensure that the child has received sufficient and comprehensible information, has been able to express themselves freely, and the child's right to respect for their privacy must be safeguarded. What the child thinks about what should be done must be given great weight and should be the starting point for each decision. If children's rights to express their views freely, receive information and privacy are not secured, it becomes arbitrary if what is done is helpful and in the best interest of the child in the concrete situation.

CHANGEFACTORY
KNOWLEDGE CENTRE

Why knowledge directly from children?
Children and young people have to feel that the school, kindergarten, support services, police and legal system are safe and useful for them. Children and young people all over Norway have experiences from meeting these systems and advice on how they can be the best possible. Authorities, professionals and students often lack this knowledge from children and young people, when frameworks and what constitutes good practice are to be determined, nationally and locally. Therefore, it must be brought in to a much greater extent and, together with other knowledge, be part of the knowledge base, in order to develop and ensure the quality of good systems for children and young people.

More than 10 years of collecting knowledge
For more than 10 years, Changefactory (CF) has systematically collected experiences and advice from children and young people about how they experience school, kindergarten, support services, the police and the legal system. In 2017, the Prime Minister opened Changefactory Knowledge Centre, to collect knowledge from children and young people about the public systems. As far as we know, there are few knowledge centres in Europe whose main purpose is to gather and disseminate knowledge directly from children and young people about the systems they are in. CF seeks collaboration with similar organisations.

Participatory and practice-oriented method
In order to collect, systematise and disseminate summarised experiences and advice from children and young people, a participatory and practice-oriented method is used. CF has called it the Changemethod. The Changemethod has been developed in close collaboration with children and young people. It greatly considers that children have the right to express their opinion, in ways that feel safe for them. The method consists of process descriptions and tools that help many diverse children and young people to participate. It's based closely on a participatory method used in action research, called Participatory Learning and Action (PLA).

Safety is most important
The experiences and advice are collected directly from children and young people in sessions or interviews. The sessions are organised with an emphasis on ensuring that they are experienced as safely as possible for the children and young people who participate. The adults who facilitate are, among other things, trained by children to meet children and young people with openness and human warmth. This is based on the main findings from children about what adults have to be like, in order for children to be able to tell honestly.

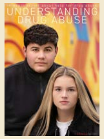
Experiences and advice are summarised
Experiences and advice from the sessions are documented in transcripts and other written and visual documentation. The data is summarised and systematised. No links are made to theory. Experiences and advice that are repeated by many children and young people in many places in the country, become the main answers. We call this knowledge directly from children.

Children and young people present
The knowledge from children is presented in reports, films, podcasts, books and online. Participants in the qualitative surveys can also be invited, as pros, in communication and professional development. The pros present knowledge directly from children to politicians, national authorities, professionals and students.

Selected publications

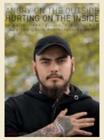
Help where we are

Advice from 110 children and young people on how low-threshold services in municipalities have to be



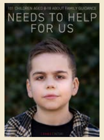
Understanding drug abuse

Advice from 50 young people about how drug help has to be for the help to feel safe and helpful



Angry on the outside, hurting on the inside

Advice from 101 children on how to meet children and young people who are angry and use violence



Needs to help for us

Advice from 101 children on how family guidance has to be for it to feel safe and helpful for children

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