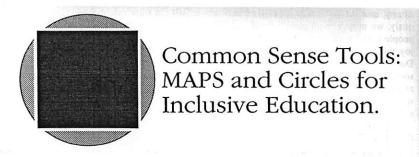
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The Prevention of Sexual Abuse of People with Developmental Disabilities Peer Tutoring The Person with Down Syndrome



MAPS and Circles of Friends are examples of strategies used to fully include and build creative, meaningful curriculum for students whose needs challenge the system. These tools help foster co-operation and collaboration both within the school and between the school and community. These tools are especially useful for students at risk of exclusion or rejection. The bigger the problem, the bigger the challenge.

Text: Marsha Forest & Jack Pearpoint

ANNIE, TOMMY, JAY, Andreas, Katherine, Becky, Erica, Mark, Greg, Miller, Peter ... the list is too long and too painful to produce. These are the names of children who have been rejected by the public schools of Canada and the U.S.A. They are black and white, girls and boys, youth and teenagers. In common is their parents' simple dream of having their children accepted and educated in one quality school alongside their neighbours. In common is their rejection from the schools of our nations. In common is the label 'disabled' pinned on them, like the yellow star pinned on people labelled

Jewish, and the pink triangle pinned on people labelled homosexual, during that terrible period called World War II.

The Nuremberg Trials confirmed to the world that pinning yellow stars and pink triangles on people was unacceptable. It was ruled a crime against 'humanity.' But today, no Nuremberg trials have ruled that IQ scores and disability labels are often death sentences to the children we 'place' into 'disability' boxes. Special education is one such disability box which we know now is neither special nor indeed educational in

any sense of the word. This is no longer 'hot news.' The data has been in for several years. The outcome for people labelled 'disabled' is a life of loneliness, poverty, and joblessness - not an outcome any family would choose for their sons or daughters. Despite this data, segregation still thrives and is considered an 'acceptable' educational placement and practice. It is still okay to talk of 'them' and 'us.'

Segregation is not acceptable. It is bad for all children. It is uneconomical, immoral, and unethical. In short, segregation must stop. This article is about how to integrate children, end segregation, and improve educational outcomes for all. No matter where we go, people are talking about the "Butwhatabout" kids. Some of the presently popular euphemisms include 'hard-toserve', 'at-risk', etc. Why don't we just admit it outright. These are children and teenagers who scare us to death, who threaten our mortality and who make us vulnerable and nervous. That is natural, normal, and human. What is unnatural, abnormal, unacceptable, and inhuman is our systematic 'boxing' and subsequent rejection of the people - or the illusions about people - whom we fear. We encourage people to square off with the fear - conquer it, and welcome all people back to our communities - complete with their mortality, vulnerability, and incredible capacities to teach us about what is important in life.

The Dragon We Call Fear

The first task is to face this dragon called fear. Mythology tells us that most 'fear' dragons are slain merely by facing them. We don't tell teachers to give up their fears. Rather, we suggest they face them - head on; take up a mighty sword and slay them, one by one.

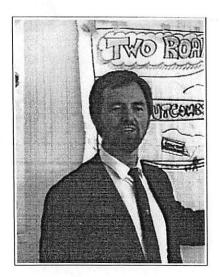
Fear is the most frequent word we hear as we talk with educators. "Don't be afraid," many people say. But not us. We encourage



Marsha Forest, Director of Education at the Centre for Integrated Education and Community.

teachers to "Be afraid! Talk about the fear. Name it! Get it on the table!" When the fear dragon is out in the open, you can kill it, go around it, or learn to ignore it. You can manage it. But as long as the fear is unnamed, the fantasy will frighten us more than any reality. Fear of the unknown, fear of failure, fear of not knowing what to do, fear of mortality. These are real fears. Once faced, fears can be overcome.

When we meet fearful teachers, we offer a little 'dragon powder.' We propose an alternative to these fearful human mortals who are just like us. Our 'dragon powders' are state-of-the-art strategies that build confidence and a better future for all our children. MAPS and Circles of Friends are tools which take the responsibility off one person and put planning in the hands of a team comprised of school personnel, family, and the children themselves.



Jack Pearpoint is the Director of the Centre for Integrated Education and Community.

MAPS and Circles are based on common sense and don't cost a great deal of money.

But beware. These strategies require three important pre-conditions:

- 1. The desire to slay the dragon of fear.
- The desire and ability to learn and change.
- The desire and ability to work as a member of a team.

We feel if teachers cannot meet these criteria, they should consider another career!

Strong words you say. You bet. These times call for strong words and bold deeds. The crimes of illiteracy, mis-education and rejection can no longer be tolerated. We know too much. Some of the successful systems in Canada and the U.S.A. have no

more money and no more brain power than any other system. What distinguishes them is leadership with guts, clear values and the vision of an outcome that spells success for all children entering the doors of our schools today.

We no longer have to prove that quality education can work. It can. It is now up to others to justify why they cannot deliver quality education to all their children.

No Magic Bullets; No Microwave Solutions; Just Hard Work. We make no claim that a MAP or a Circle as described in this article is a magic bullet or microwave solution. These strategies, developed and practised for a decade with live children in real school systems in Canada and the U.S.A., are simply tools in the arsenal for quality education for all - a dream we believe to be viable and necessary.

Making a Map

This strategy has been pioneered and used by many teachers and families in the past ten years. The laboratory has been two school boards in Canada. First and foremost, these two boards (approximately 20,000 students each) believe wholeheartedly that:

- all students belong in regular classrooms - no ifs, ands, or buts,
- ordinary teachers can teach all children,
- necessary supports will be provided when necessary,
- quality education is a right, not a privilege,
- outcomes must be success, literacy, and graduation for all,
- creative alternatives will be available for populations not succeeding in the ordinary fashion (i.e., they developed store-front schools, cross age tutoring, alternative high school programming as required).

What we've learned in ten years is that we can welcome all students into our nation's schools and classrooms - if we want to. This is regardless of the complexity of children's needs - be they physical, mental, or emotional. After all 'untrained' parents have been doing it for years. As one of our friends said after the birth of her daughter, "Jane didn't come with a set of directions. If we figured it out, so can a school. After all, teachers are paid for it, we're not. And they are trained educators, and we're not! It should be easier for them. Basically, it is very simple. If they want Jane, they'll figure it out just like we did. All it takes is time and love."

MAPS

MAPS is a collaborative action planning process that brings the key actors in a child's life, together. In the spirit of co-operation, this team creates a plan of action to be implemented in a regular classroom setting. It is not a case conference or an Individual Education Plan (IEP), but the results can certainly be used on any IEP form.

MAPS is facilitated by two people - practising what it preaches - 'together we're better.' One person acts as the 'MAPS recorder,' making a public record (preferably using graphics) on large chart paper. This is an essential element of a MAP. The other person is the 'host' who welcomes the group, explains the process, and facilitates the MAP.

Essential Elements of a MAP:

- Co-facilitation (host and recorder; can be interchanged).
- Graphic recording with colourful markers on chart paper.

- Hospitality a personal and informative atmosphere (snacks, beverages, tokens of thanks).
- All key people in the child's life present and participating.
- Focus person and his/her siblings and friends present and person participating.
- 6. Key issues addressed: What does the child and /or family want?
- 7. Decision to meet again (with a date).
- Concrete plan of action (actual things to do right away).

Without these essential elements the plan is not a MAP. It may be something similar, but a MAP must have the above eight elements (or have a good reason to leave out an element).

A MAP is made up of questions that can be conceptualised as a circle. Each key must be used, but there is no particular order. The facilitators decide on their direction depending on the needs of the group.

MAPS Part I

Question 1 - Setting the Tone and Introductions.

Before the MAP the facilitators set up the room in an informal semi-circle with comfortable chairs. Chart paper and clean markers should be ready. Snacks are available for people before the session begins. Colourful name tags are ready. The facilitators invite the group to be seated and one asks everyone to introduce themselves. Each of the participants explain who they are and what their relationship is to the focus person, who, for the purpose of this article, we will call Mark.

Question 2 - What is a MAP?

The facilitator then asks the participants to think of a MAP and asks, "What is a MAP?" Here is how one recent group answered:

"A MAP shows direction."

"It tells you how to get from one place to another."

"It shows you how to find stuff."

"A MAP tells you where to go."

Facilitator:

"That is exactly what we are here to do. To show direction for Mark's life, to help him and his family get from one place (the segregated class) to another place (the regular class).

The MAP will also help us figure out how to find the 'stuff' that Mark needs. If we all work together, we can decide where to go next. Together we can create a plan of action that we can put into practice for Mark, starting right away."

Question 3 - What is Your Dream?

This is really the heart and soul of the MAP. The facilitator must build an atmosphere so that the family feels comfortable to say what their dreams, hopes, and wants really are.

Facilitator:

"If you could dream the dream you really want, if you could have anything with no holds barred, what do you really, truly want for yourselves and for Mark? Money is no object. Don't hold back. Let yourselves be free to really say what you want. Don't ask for what you think you can get. This is different. This is what you really want and dream about or pray for."

There is often a deathly silence at this moment. It is essential. Do not interrupt. Wait. Allow the family time to build up their courage to get out their real feelings and hopes. If this is rushed, the whole MAP may be futile.



"My dream is that my child be happy, be included in school, ride to school with his sister, be invited to birthday parties, have a hamburger with a friend, and have the phone ring just for him."

When a facilitator asks the question about people's dreams with a full heart, so that people gain the confidence to risk stating their buried dreams, profound things often happen. A pattern has emerged after years of asking this question. Parents all over the continent have told us that the MAP empowered them to dream again. As one Colorado parent stated, "A MAP is a way of restoring the dream to a family." With older teenagers or adults, the person states his/her own dream. The MAP restores a dream to the individual.

Butwhatabout. 'But' someone out there is thinking. 'Butwhatabout' the person who can't speak? We have done many MAPS with children labelled 'Non-verbal.' Although these children don't speak, they certainly communicate. And if the group knows the child well, someone will be able to articulate their own dreams for the child, and also the dreams they think the child might have.

Facilitator:

"If Mark could speak, what do you think his dream would be?"

Families often weep openly as they tell us, "My dream is that my child be happy, be included in school, walk or ride to school with his sister, be invited to birthday parties, have a hamburger with a friend, and have the phone ring just for him."

One 12-year-old girl told us, "I want a trip to Hawaii and a job with computers. Also a pet dog." She was clear as a bell!

One parent of a medically fragile child told us, "I want my child to have one real friend before she dies. My nightmare is that my child will never know friendship." (This little girl did die soon after, but because she had moved into a district that welcomed

her, the mother did get her wish. The entire third grade class attended her daughter's funeral. The family knew that their daughter had made real friends in her all too short life.)

Question 4 - What is My/Our Nightmare ?

Many people consider the nightmare question the hardest to ask. We believe it is one of the most important because the MAP must identify the nightmare in order to avoid it. Unless the MAP prevents the nightmare, it is a waste. Unless the outcome of the plan of action is to prevent the worst from happening, all we are doing is simply 'busy work'.

In ten years of doing MAPS, these are the most consistent responses to this question: "My nightmare is that my child will end up in an institution with no one to love him/her." "We will die and my child will be alone and put in a group home." "My child will never have a friend."

No one has ever said, "I'm afraid my child will not get an A in maths or learn phonics."

No one has ever said, "I'm afraid there won't be a proper functional curriculum."

This question often breaks the ice between warring factions. When school staff see that the parents want what every parent wants for their children, barriers break down. We have seen wars melt into peace treaties. A Kentucky woman broke down describing how her 18-year-old son was currently living out his nightmare, institutionalised, after having blinded himself. "Our family is in the nightmare," she wept. "All we wanted, all we want now is some shred of human kindness and friendship to our son."

Facilitators do not have to be familiar with the person or the family, but must know the MAPS process inside out. The facilitators must first and foremost believe

150 percent in the fact that full inclusion is possible for all! The facilitators must be good listeners - able to hear great pain without providing immediate advice and solutions. The teachers and school personnel are a part of the group. The facilitators can be school personnel or an external team. The facilitation rule is to pull information from the group and move it along into an action plan. The recorder creates a photograph of what the group says with colour, graphics, and also summarises what has been said before going to the net step.

Question 5 - What is the Story?

Facilitator:

"Please tell us your story. What are the most important things that have happened since Mark was born? I know you can not go on and on with this so I will limit you to

The MAP Questions — A Mandala

Introductions

What is the story? history?

What is the dream?

What is the nightmare?

What is the person good at doing? What are his/her needs?

What are his/her needs?

What are his/her rights, stalents?

5 - 7 minutes. Tell us what you feel is really important for all of us to hear and to know about Mark's story."

The facilitator must be careful not to make this a case history. She/he must listen with all heart, soul, and body. The recorder writes the story - words, pictures, and images. The facilitator also asks the participants to listen with their hearts.

Facilitator:

"Don't listen just with your ears. Listen with your whole body. Don't be judgmental. This is not a trial. Try to feel - hear what the person is telling you from inside - as if it were your own story."

We often ask this question before the dream. It depends on the tone and mood of the group. The recorder summarises the story after the family or person has com-

pleted their thoughts being sure that the facts are correct and the essential elements of the story are there. The recorder should request the assistance of the MAPS team to correct spelling, facts, etc. Making simple errors (especially with people's names) can be very upsetting to some people, so legitimize corrections. Request assistance. This increases group participation and ownership.

Questions 1 through to 5 are Part I of a MAP. It is often necessary to take a break at this point. The second part will be lighter, faster paced, and move toward the action plan.

MAPS - Part II

Question 6 - Who is Mark?

We like to draw an outline of a person on the chart paper and hand out 'Post-It' notes to change the mood and motion of the MAP. This is a brainstorm session. Each person writes a word or phrase (one per 'Post-It' note) and posts it on the outline. This gives us a snap-shot of the person. A recent MAP of a 12-year-old boy had these words: curious, handsome, determined, likes good snacks, always hungry, potential, my son, dimples, pretty ordinary, my brother, very active, pest, a little brat, somebody's great friend someday, an interesting boy, lively, likes to play with drums, great family.

The recorder attempts to group the words to get a picture of Mark. We sometimes ask, "What have other people said about Mark in the past?" What words have been used before in other meetings? In this case these were the words previously used to describe Mark: retarded, developmentally delayed, autistic, severely autistic.

These should be posted separately, but the recorder may want to highlight the dramatic differences between the two portraits of the same person.

Question 7 - What are Mark's Strengths and Unique Gifts?

Another list was generated: happy, beautiful boy, loving, friendly, he can look you in the eye and smile, gives a lot, he has a 'look,' helps to put things in perspective, makes you feel good.

Question 8 - What does Mark Like to Do? What is Mark Good at?

This brainstormed list is important as it gives us many ideas for the curriculum and

daily program: Mark likes to throw balls, play with ropes and strings, climbing in parks, eating, relax, swim laps in the pool, play in water puddles, go skating, play in clothes closets, be with people.

By this point we have generated an enormous volume of information on Mark. We ask, "First and foremost, what do we all need to make this (the dream?) happen? What does Mark need? What does Martha (the teacher) need? What does the family need?"

At this MAP the only people present were Mark's mum, dad, teenage sister, and a dedicated teacher/friend. When it came to Mark's needs, there was a real consensus that Mark "needs to be involved and to meet people his own age." The family needed him to meet other children so his mother could begin to build a life of her own. The family agreed that a 'worker' (to help build community integration) would be a godsend. They wanted that person to take Mark to local places where he could 'get involved' with other kids. The job description for that person was developed from what was said at the MAP:

- · Find places where he can meet kids.
- · Find kids to spend time with him.
- · Go to the youth centre.
- Get involved in trips, swimming, and activities.
- Develop more communication skills.

Question 9 - The Plan of Action

When you frame the needs question carefully, it flows directly into a plan of action. In some circumstances, we might draw the timetable and have the other students brainstorm all the activities that Mark likes and could do. Then we explore the logistics. If Mark is going to get from history to gym and be dressed in ten minutes, he will need

help - a guide. Who would be willing to help? We link specific people to specific times, places, classes, activities.

In this instance, the family enthusiastically agreed to plan a pizza party at their home and invite some neighbourhood kids that weekend. Together with Greg, the teacher/friend, they started to look for a community integration facilitator. Greg agreed to facilitate another MAP with a wider group in one month. A date was set.

A MAP must be concluded. The recorder walks/talks the group through a summary of the charts and presents the charts to the family as a gift - along with other gifts such as a plant, a cake, something sweet, something that grows.

Before it ends, the host/facilitator asks each participant one more process question.

Facilitator:

"Will you give me one word or a phrase to sum up your experience of this MAP. Off the top of your head ... the first word that springs to mind ..."

Here's what this group said:

Mum: "I'm relieved. Great session."

Dad: "Very positive. Thanks."

Sister: "Awesome."

Mark: (gives us all a really big smile.)

Greg: "Fabulous and positive."

The Kaleidoscope

The metaphor for the MAP is a kaleidoscope. The kaleidoscope is a magical toy, a mysterious and beautiful tool that changes constantly. Through the eyepiece we see little bits of beautiful colour turning together into an ever-changing luminous melody of colour and light.

We see the kaleidoscope as the outcome of each MAP. It is a medley of people working together to make something unique and better happen. It is more than anyone can do alone. It proved what we strongly believe - together we're better!

Circles of Friends

Stop. Take 30 seconds. Try to imagine a world in which you did not have a single person who truly loved you. Imagine having no family and no friends. Imagine that you see only paid personnel in the morning and at bedtime. Imagine a world where none of your peers speak or walk. Take a moment to remember how it feels to be that lonely and isolated.

Recently we met a young woman who literally had no one in her life. She had been abandoned by her parents at the age of four and placed in a group home for children with 'severe to profound mental retardation.' As we did her MAP, she sat with us and listened intensely to the conversation. We were told that she banged her head and screamed constantly. The person we observed sat still for two hours and listened intently. What did she hear? What did she understand? It is our belief that she heard and felt our concern, that through her blind eyes she saw love and people who were afraid for her life. We believe she responded to that caring by sitting with us for two hours. She is 16 years old and knows no one her own age.

It was clear that an intentional circle needed to be built immediately. Diane had been physically present in a regular high school but spent her days in a segregated class. She was present - but invisible. No one really knew her.

The school called together a group of teenagers and teachers who expressed an interest in helping Diane.

"How would you feel if your life looked like Diane's?" we asked.

One young woman said quietly but without hesitation, "I'd commit suicide."

Others said, "I'd sleep all the time." "I'd take drugs." "I'd drink." "I'd kill someone." They saw immediately that what Diane needed most was to be with them - to get out of the segregated room. They brainstormed places they could go with Diane. There was a rock concert coming up. One student volunteered to take Diane with her and her other friends. Another decided to visit Diane and have dinner with her at the group home. The students thought Diane would like the music and cooking classes which were noisy and the teachers were 'pretty cool.' The ideas flew. Diane sat through the meeting with a smile as she gently rocked back and forth, back and forth.

Several teachers decided to get involved. Rather than blaming themselves for what they had not done in the past, they switched their energy into actions they could deliver in the future.

The result: six months later Diane has regular visitors to her group home; she has gone out more in six months than in the past ten years; and one teacher and student seem to have formed a special bond with her. They have invited Diane to their homes for dinners and Sunday outings. It's a good start. Best of all, Diane is out of the segregated room and goes to music, cooking, and other regular classes. She hangs out in the lunch room and has stopped poking the corners of her eyes and screaming as much as before. Is Diane 'cured'? No! Does she now have people to talk to, things to do, a life to look forward to? Yes! Equally important, Diane's classmates are learning and gaining even more than Diane. They are getting 'experience' (hands-on training has always

been the best) in problem solving (number one issue in the curriculum) with a real and relevant problem. They have to create curriculum, timetables, and trouble shoot with Diane. They are learning to manage teachers, manage behaviour, and confront values issues. Their acquaintance/friendship with Diane may be one of the most important learning activities of their lives. There is still a long way to go, but the circle has started. Diane has a dream, and her new friends are part of it.

Conclusion

To us MAPS and Circles are like building a good foundation for a house. What good is a castle if it is made on sand? What good are communication skills if you have no one to talk to? What good is physical mobility if you have nowhere to go? What good is life itself if you have no one to share it with?

The Centre for Integrated Education and Community (CIEC) is busy refining its training institutes and workshops so that we can spread the word about the beauty that lies in the heart of inclusion. We have no pretences that we have THE answer. We do, however, have years of experience and hundreds of success stories that tell us full integration and quality education are indeed possible.

Attitudes are the major barrier and are no longer an adequate excuse. We must welcome all children now. It is their right. Our future depends on it. There is simply a need for action - NOW!

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