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marketresponseinternational



Project #2210

April 17 2013

# K - 12 Education Study for Students with Developmental Disabilities

prepared for:

**The Minnesota Governor's Council on  
Developmental Disabilities**

designed and implemented by:

marketresponseinternational

## Forward:

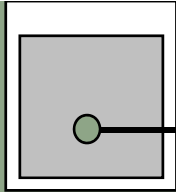
This is the story of the public education journey, which typically begins when a child enters school around age five, and ends with graduation from high school.

It's a story about transformation, from childhood to adulthood. The transformation is successful when the *graduate* is prepared for a productive and fulfilling adult life.

Our focus, however, is not on the typical story, but on the students who are diagnosed with developmental disabilities. Their education journey is more difficult, and transformation harder to achieve.

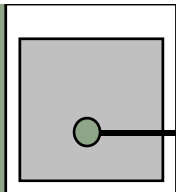
Thomas A. Pearson  
Managing Director

marketresponseinternational



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# Introduction -- letter to the reader

Dear Reader,

Thank you for your interest in this report from the K - 12 Education Study for Students with Developmental Disabilities. This report mainly consists of stories told by parents of students with developmental disabilities, and some students themselves, revealing their true experiences in the education journey in Minnesota. You may be moved by these stories, as we were, and we encourage you to share this report with others who may have some interest in Minnesota public education. We entirely believe that the more people who hear these stories, the more likely that positive change will occur.

## **Narrative Research Methodologies**

For this study we chose to employ Narrative Research methodologies, which are relatively new to the United States. In the summer of 2012, professionals in our company became accredited practitioners of the Narrative methods designed by the Cognitive Edge Network\*, at an Accreditation seminar in London. One of our European colleagues (Willem Brethouwer, Managing Director of MarketResponse NL) has several years of experience with Cognitive Edge Narrative methodologies, and he traveled to Minnesota to assist on this Public Education Study. (Thank you Willem!)

Narrative methodologies are particularly suited for *pre-hypothesis research in complex domains*, and we believed this Education Study was perfectly in line with those parameters. Pre-hypothesis means we conduct the research with no preconceived ideas of what we will find; rather, we let the respondents define the narrative of the domain through the telling of their own experiences.

We believe the domain of education for students with developmental disabilities qualifies as a *complex domain*, which by definition means that cause and effect are only recognizable in hindsight. Narrative Research methodologies from Cognitive Edge are specifically designed to reveal the patterns that define people's perceptions and behaviors in these *un-ordered* domains.

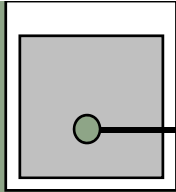
## **Much Appreciated Assistance from MACE**

We began this study with an interview and discussion of the project with Jan Ormasa, Executive Director of the Minnesota Administrators for Special Education. Jan's initial guidance to us, and her assistance in informing and recruiting special education directors from selected school districts in the state were essential to the successful implementation of this study. Thank you Jan! We very much appreciate your partnership on this study. We know we could not have done this without you.

Kind Regards,

Thomas A. Pearson, Managing Director  
MarketResponse International USA, Inc.

\* The Cognitive Edge Network, headquartered in Singapore, is a Network of experienced professionals in private and public sector organizations. Membership is attained through participation in an Accreditation program.

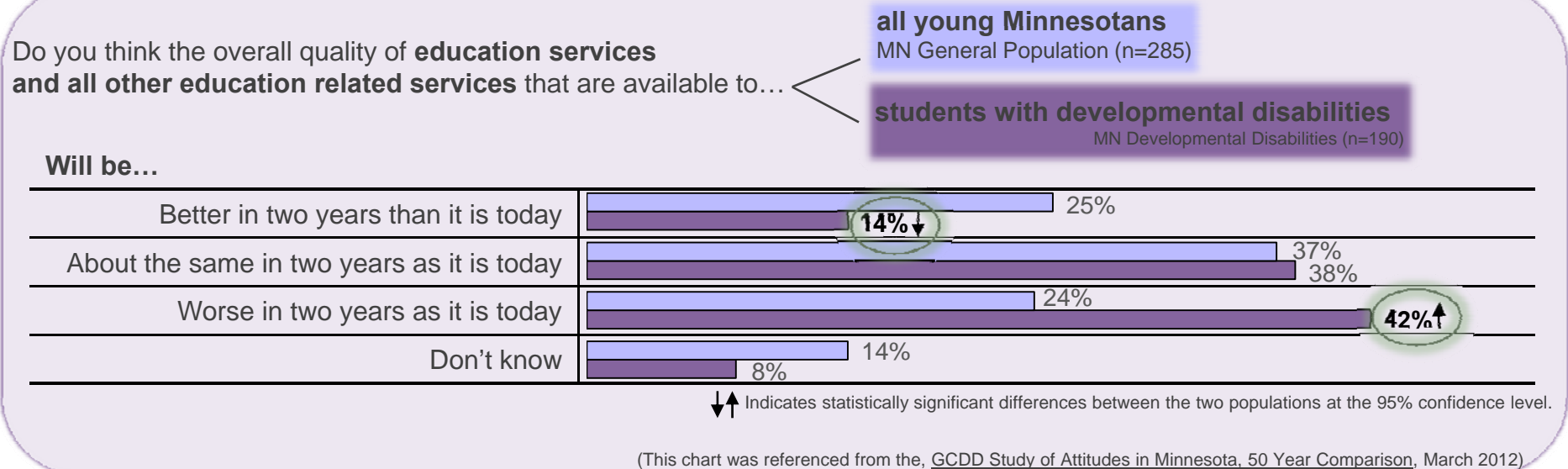


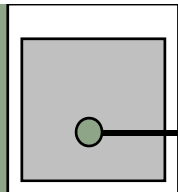
# Introduction -- project overview

## Why this Study was Initiated

In Q1 2012 the Minnesota Governor's Council on Developmental Disabilities (GCDD) commissioned MarketResponse International to conduct parallel surveys among MN heads of households representing the general population of Minnesota, and the population of households with a son or daughter with a developmental disability. The purpose of the study was to compare attitudes between the two populations related to education, employment and abuse. The findings regarding education revealed a significantly more negative outlook from the households that had a member with a developmental disability regarding the near-term future of education services.

That finding prompted the 2013 research study summarized herein, which was designed to explore the education experience of students, families, teachers and other education providers, to better understand the issues, challenges, and opportunities facing students with developmental disabilities, and their families, in the state of Minnesota.



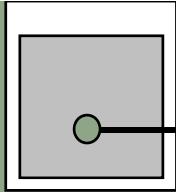


## Introduction -- methodology

The basic premise of the narrative methodologies employed in this research are:

- Humans are fundamentally shaped by, and shape, the narrative structures of their existence.
- Narrative stories and anecdotes tell us **what people really internalize** based on their experiences.
- People's perceptions are hidden in their stories and anecdotes:
  - What people retain from and *take out* of their experiences and pass on to others;
  - This *take-out* influences their decisions and behaviors.

**Effective human engagement involves the awareness and understanding –and sometimes disruption– of these narrative patterns.**

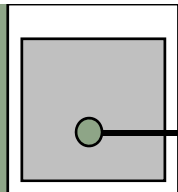


## Introduction – research respondents

We collected over 200 stories and anecdotes from 110 individuals, including: students with developmental disabilities, their parents, teachers, case managers, special education administrators, self advocates, and others:

Date (Q1 2013)	Groups / Individuals	Sample (n)
2/6	GCDD Public Policy committee narrative focus group	14
2/22	Partners in Policymaking <sup>®</sup> narrative focus group	30
Q1	Teachers, Case Managers, Administrators	11
3/4-19	1:1 Interviews w/ students with dev. dis.	9
3/4	St. Paul parents narrative focus groups	17
3/5	Hopkins parents narrative focus groups	17
3/19	Brainerd parents narrative focus groups	12
Total participants		110





# Introduction – participating districts

## What lead us to our three participating school districts?

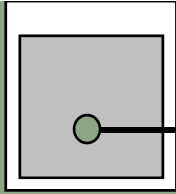
One of our goals for this project was to reach out and obtain stories from parents in different sized school districts. We sought out **a large city district**, **a suburban district**, and **a rural district setting**. Jan Ormasa, Executive Director of MASE, (Minnesota Administrators for Special Education) forwarded an email request written by MarketResponse International to its MASE members; the following three District Directors responded:

- (1) St. Paul Public Schools, Elizabeth Keenan – Special Education Director
- (2) Hopkins School District, Linda Gardner – Special Education Director
- (3) Brainerd School District, Gaynard Brown - Special Education Director
  - Brainerd Special Education services extend to rural areas beyond the Brainerd community, including 6 smaller rural districts, and 3 charter schools.

We very much appreciate the time and efforts of these Directors and their staff members, for their participation in this study and their assistance in organizing meetings with parents, students and others in their districts.

### GCDD Partners in Policymaking® Class:

As we were searching for a fourth non-metropolitan district to opt in to this study, an opportunity presented itself to conduct a full narrative focus group/workshop with 30 advocates and self-advocates attending a GCDD Partners in Policymaking® class. Some of the public education experiences described by these attendees were included in this report; and the narrative themes that emerged from this group of Partners played a role in shaping the analysis and interpretation of all the stories we heard from all respondents.



# Introduction -- Making sense of the stories

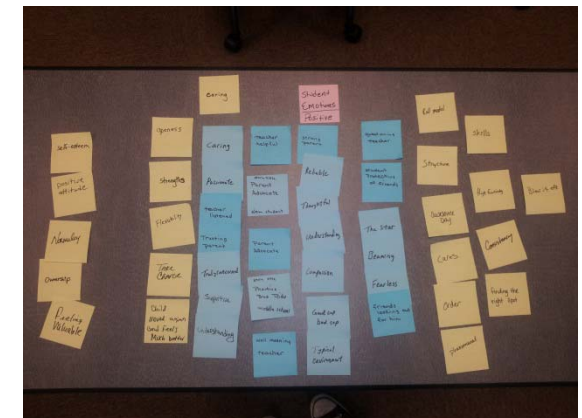
The narrative focus groups each lasted 3 hours or more, and included a 3-step story telling and sense-making process. The participants were divided into 3 groups for story telling and *tagging*:

While one person told a story the others at his/her table wrote key words on yellow and blue Post-It notes.

Post-It Notes from ALL stories were randomly placed on tables whereby the respondents then sorted them into coherent groups.

In each location the respondents created several clusters of story elements and character descriptions, revealing the common themes, characters and values at play in the stories. A title was then given to each cluster grouping.

This is a sample of a cluster taken from one of the five narrative focus groups.

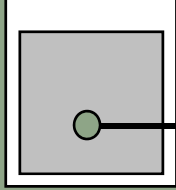


## **Contents:**

**1:: Introduction**

**2:: 7 story themes**

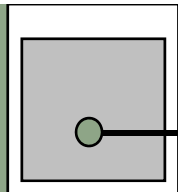
**3:: Future Back**



## 7 story themes identified

7 themes emerged from the 200+ stories and anecdotes:

- 1) Emotional Roller Coaster
- 2) Special Education in its Own Bubble
- 3) Through the Cracks
- 4) Fear of Parental Empowerment
- 5) Education Heroes
- 6) Integration to Inclusion
- 7) Transformation

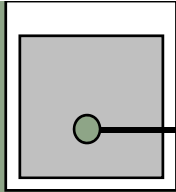


## Validating the seven themes

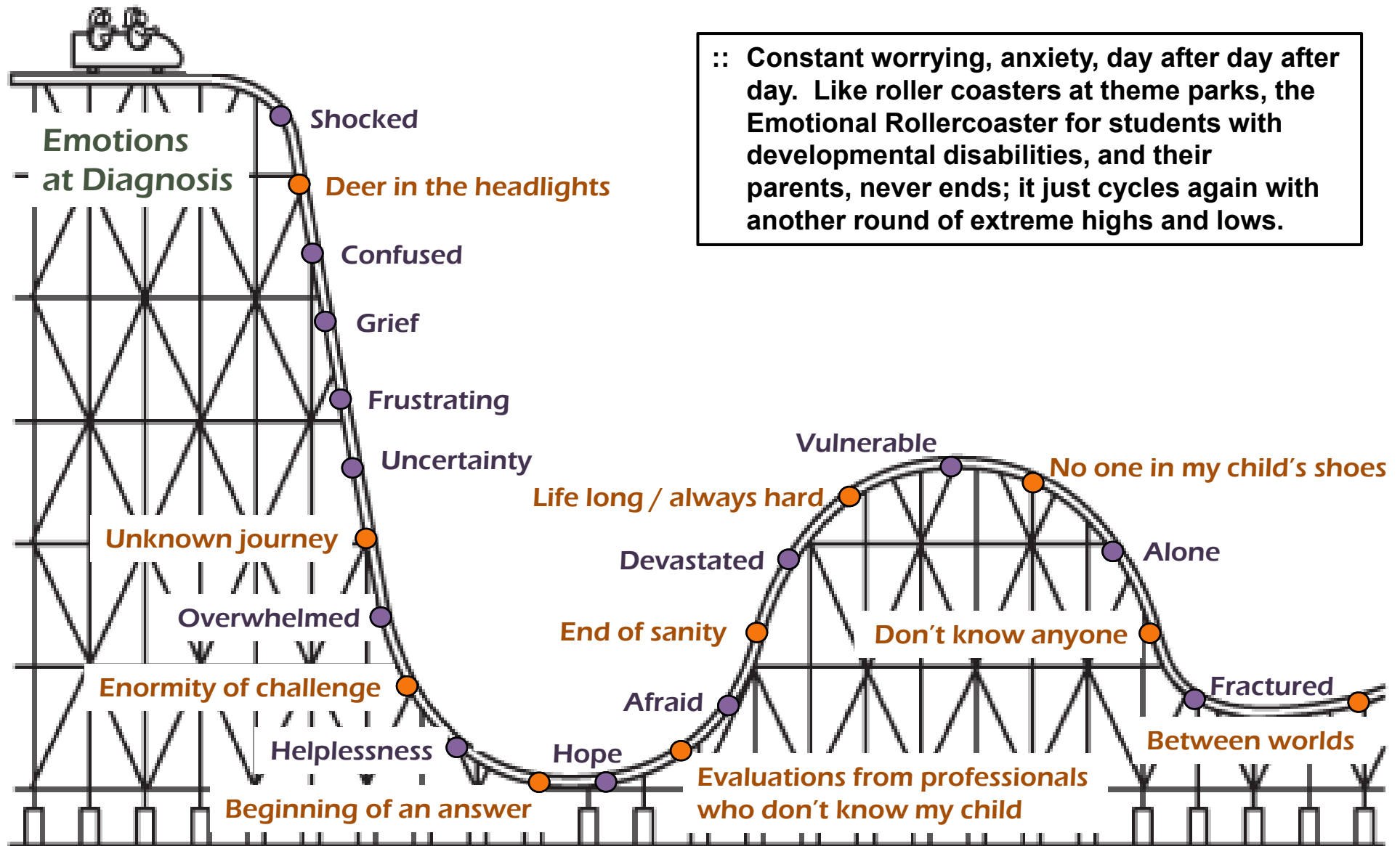
At every focus group/workshop, the participants broke down all stories into their relevant elements, then grouped those elements into what they perceived coherent clusters. The participants assigned titles to those clusters, and had a spokesperson describe the cluster to the entire group.

Once all the groups were completed, the qualitative research professionals from MarketResponse laid out all the clusters from the 4 workshops, and looked for commonalities. In our analysis, MarketResponse identified 7 distinct themes which we believe best captured all the relevant dimensions of the cluster titles from the participants. These themes best define the narrative of public education for students with developmental disabilities in Minnesota.

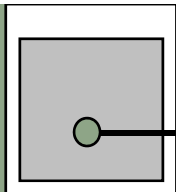
And while the creation of the themes involved some subjective interpretation, we believe in the validity of the analysis, because it provides a meaningful structure for organizing and presenting the distinct subjects represented in the 200+ stories and anecdotes we heard.



# 1) Emotional Rollercoaster



:: Constant worrying, anxiety, day after day after day. Like roller coasters at theme parks, the Emotional Rollercoaster for students with developmental disabilities, and their parents, never ends; it just cycles again with another round of extreme highs and lows.



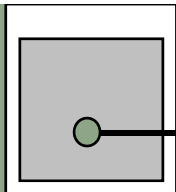
# 1) Emotional Rollercoaster

*“We feel helpless, we feel scared for ourselves, our children, for what is going on in the schools while we are away from them. There is a lot of frustration, a lot of it is overwhelming. We don’t get a day off.”*

## Future Unknown

*IEP meetings are not always great experiences, when you go in and there’s a psychologist who’s been working in the business 30 years, and he says, “Well you know, all kids who are Down Syndrome will never do this, this, and this; and he is never going to be able to sit through math by the time he is in first or second grade...” Those are really hard things to hear about your child.*

*Know your rights is very important, what do we have for rights with our children. What kind of rights are we going to have with them when they turn 18. That is a scary thing to think about.*



# 1) Emotional Rollercoaster

## Challenging Changes

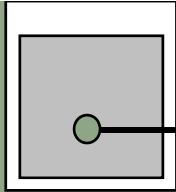
*Now I'm seeing the district that I love start to cut back because of funding shortages; and I'm thinking, here we go. This journey is not a static thing, it's constantly changing.*

*We moved years ago from Washington State to another school district in MN. I had everything done a month prior, I thought I had everything set up for our son. Once we established him, they told me 5 months later they were moving again; so they moved him to another school. The next year he had to transition to middle school so he went to another school. So in 18 months he went to 4 different schools. I thought "What did we do? Why did we do this? We moved to the worst place on the planet for him."*

*Even though I'm a huge proponent of neighborhood schools, I'm unhappy with this (recent district) decision that you have to go to the school in your neighborhood. He's been going to a great school; he's been there for 2 years. But they got rid of the (special education) program, and now he has to change to a new school, away from friends who have grown together. I think this neighborhood school program is good in a sense, but I also think it promotes discrimination and segregation against children with disabilities. As a taxpayer and parent I am extremely, extremely unhappy about this.*

*My grandson, who has autism, said that if they change his school he's going to quit going. I said, "You can't just quit." He said, "Watch me." These kids thrive on having a routine, and anytime you try to change it, you have to explain it to them, over and over. And they might never get it, if they don't like (the change).*

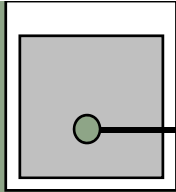




## 2) Special Education in its Own Bubble

:: In some schools the students with developmental disabilities are perceived to be the exclusive responsibility of a specialized group of special education teachers and support staff, and not a concern for regular education teachers. In these environments, special education is in its own bubble – isolated, not integrated, in a different world.





## 2) Special Education in its Own Bubble

***“His teachers know him spot on, if he is having a bad day or an episode they know exactly what to say to deal with him. But the lady in the lunchroom doesn’t, the play ground person doesn’t, the physical education teacher doesn’t. Not just the special education staff should be trained to deal with our children, but the rest of the staff as well.”***

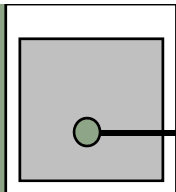
### Different Worlds

*Our public school system has a system of educating kids, but our kids do not fit that system. The people are great – well-trained and passionate about what they do; but it’s the system that’s limiting.*

*The previous school district we were in didn’t know what to do with (our son) because they didn’t know where he fit. He’s a special needs kid, but he’s high functioning. So he doesn’t fit in the regular classroom, but he (also) doesn’t fit with the kids who need considerably more attention than he does. He’s kind of right in the middle. There were times when they just put him in a room by himself with a computer and had him do story problems or something like that. And sometimes he would just wander.*

*If you are a kid in special education, you are a kid between worlds. When you are between worlds you are kind of like an immigrant; there is a distinct culture and it takes time to learn it. The role of the parent is to be the connective tissue between the world your child is in and the world that the education system is. We moved our family from Oakland, California to here. When you are between worlds you have to move.*

*We feel the entire staff should be trained on our kids. The entire staff should feel and understand kids on the spectrum, or other special needs kids. (But instead) we feel we (parents) are the teachers, teaching the teachers.*



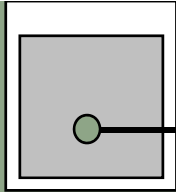
## 2) Special Education in its Own Bubble

### Unprepared

*With a child with developmental disabilities we have to advocate every day. Even though our experience has been really good in the (city) school district, we transitioned from elementary school to middle school this year, and it was a whole new ball game. It took months for them to set up the programs that were needed for our son. We're not experts, but we know what works and we had to really advocate hard for him, every day. The teachers were all very capable and well-meaning, but they didn't have a plan for our son; they weren't prepared for him.*

### Rejection

*When William was in first grade there was a morning when all the parents and kids were to come to the school for a pancake breakfast, and we thought, "Great, we'll do it!" So we came with Will, we sat down at a table and all the other parents and kids got up and left. And my husband and I looked at each other and said: "Did that just happen?" It was shocking! We ate breakfast by ourselves, dropped Will off in his classroom, and we never did anything like that again. Even in a great school like ours, there was no sense of community that day.*



### 3) Through the Cracks

:: Because of ignorance, or simple lack of awareness and sensitivity, students with developmental disabilities are at risk of slipping through the cracks of a protective and nurturing system, resulting in exposure to undesirable situations and setbacks.

## Through the Cracks

Unprotected

Horrible experience

Child shut down

Staff lied

Did not believe student

Misunderstood the situation

Not thriving

Teacher bullies

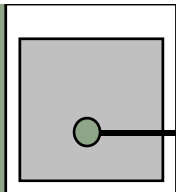
Scary

Hated school

Bullied

Unnerving



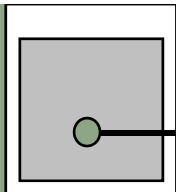


### 3) Through the Cracks (continued)

#### Over-reaction, Escalation

*He blew up. We still don't know the whole story, we've gotten bits and pieces. What made him blow up was the fruit game. He was the center of attention (which he does not like). He asked many times for a break and each time he asked he was denied a break. Finally after asking five times he blew up. He was put in to the quiet room...I got a phone call that I needed to come and get him. The police have been called, and he has been handcuffed. We were told he had destroyed the entire room. My husband and I got there within 15 minutes, and it was as if the room had not been touched. He was charged with disorderly conduct, he got a ticket, we had to go to court. This happened in November, the court date was set for December 17. The child was in such disarray, completely mortified, scared. As parents, since it was getting closer to Christmas, we asked him: "Can you give us a list of what you want." He said, "No, if Santa comes you can just put them on my bed, I'll get them when I get home." He went from not wetting the bed to wetting the bed.*

*My daughter pushed the aide, but instead of taking her to the case worker, they took her to the assistant principal for the 11<sup>th</sup> and 12<sup>th</sup> grade. He told her the next time she pushes anybody they are going to put her in school suspension, or she can be arrested. So I went to the school myself and almost got arrested because I confronted him on this. This Assistant Principal thinks he is God Almighty. He thinks he can bully around special education kids too. It all boiled down to where he was made to apologize to my daughter, and he is not to have any conversation with my daughter, except through the case worker, which is where they should have gone to begin with.*



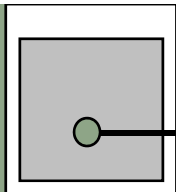
### 3) Through the Cracks

***“They slip through the cracks. We can feel them slipping through the cracks and we don’t know what to do to prevent that from happening.”***

#### **Exposed and Unprotected**

*What we’re being told now is that (the school) can’t integrate the special education students into regular classes, because we don’t have the funds to support it. So we’re told that integration is happening at recess.*

*All year long he kept talking about how he hated school; everyday it was a chore to get him on the bus. So I finally sat him down ...he was being relentlessly picked on throughout the day. Of course they don’t do it when the teachers are around. It happens in the hallway, the lunchroom, waiting for the bus. So I asked him to go to the adults and tell them what was going on. He came back said he did that, they would say they didn’t see anything and couldn’t do anything. Meanwhile his grades are going down the toilet, he hates being at school. His social skills class is his one shining light in his dark and dismal day. One day I got a phone call. The roller mats that the chairs go on, my son found one that was broken, and he took a piece of it and made a weapon to defend himself. So it came down to him actually scratching a child with this piece of plastic. They called me and I thought he was going to be expelled! Now he did this, not that it is right, but now he is going to pay an ultimate price for this. So I went in to the school and to my surprise I had nothing but apologies, up and down: “We are so sorry, we should have listened to him, should have listened to you. We went and talked to other kids...they said that every day he was being picked on.” They are not stupid children, they know that when (the teachers) turn their backs, others are going to pick on these kids. His whole 9<sup>th</sup> grade was dark and dismal.*



### 3) Through the Cracks (continued)

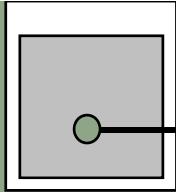
#### Exposed and Unprotected (continued)

*From the day he was in middle school, there was one child that hit him everyday, everyday, everyday! I told him, “You need to talk to an adult about this.” So he did. Then he said, “Mom I am not going to talk to them anymore, they don’t do anything, I’d like to kill myself and not be here any longer. I can’t go to school anymore.” He was hit everyday and finally he reacted and he pushed this kid back. And then the school called me; they were angry, they were mad at me, and at my son. I said, “Did he come to you for help?” And they said “yup.” I said, “Did you do anything about it?” She said they can’t separate them. I said, “I am sorry, but you are not protecting my son either.” Brain surgery would be much easier than trying to figure out the school district mess.*

#### The Bus Ride (an unordered domain)

*The first time we put Andrew on the bus was **scary**, because he’s non-verbal and can’t tell us if something happened. So to put our trust in these people he’s never met, for a large portion of his day was **unnerving**. For all kids I think the bus is kind of a scary place, but (more so) for Andrew in particular.*

*My child can have a very good day at school, but after the bus ride home he’s just spent; freaked out and upset. It’s a big bus, with a lot of kids, and they’re cussing, and they’re throwing stuff, and they’re wrestling. There’s no order in (the bus), and my son is all about order. He’s very obsessive about rules and order.*



## 4) Fear of Parental Empowerment

:: In every group the parents talked about the lack of opportunity, through the school district, to get to know each other, to share their stories and resources with each other. There is no opportunity or encouragement to speak with a common voice.

Unknown journey

Kept in the dark

Exhausted

Strength  
in numbers

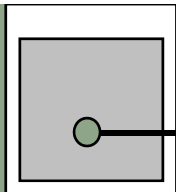
# Fear of Parental Empowerment

No map

Can't do this alone

No guide book





## 4) Fear of Parental Empowerment

***“I really feel as though the district really does not want the parents of children with special needs to form a collective, to be a group that’s really connected, because I think they’re afraid of what we would do, if we were to stand up for our rights.”***

### **No Map, No Guidebook**

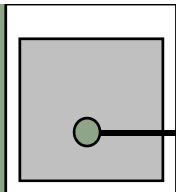
*I think being a parent of a special needs child in public education is like being on a long journey without a map. There’s no IEP (Individual Education Program) for Dummies book, or guidelines showing, “Here’s the ABCs of all the resources that are available, that could be useful or that you’ll need.” I feel like the whole process is by trial and error. Sometimes you feel like you hit a home run, and sometimes you discover something that you wish you’d known about five years ago.*

*If you are diagnosed with cancer there is all this information laying out the process, step by step, of everything you will be going through. Your hand is held and comforted by professionals, and support groups all along the way. Why isn’t there documentation, support groups, for us? What resources are available to us both in the school and outside the school? We need that help.*

### **Exhausted**

*Advocating for my child would be a full time job, if I didn’t have a full time job. I feel like we (the parents) are taken advantage of by the school district because we’re tired, we don’t have the fight in us. Taking care of a special needs child takes all of your time and energy.*

*A lot of it is overwhelming because we deal with this day, to day, to day, and we don’t get a day off.*



## 4) Fear of Parental Empowerment

### IEP Frustrations

*When I was just coming into all this I was introduced to the IEP. They just put it in front of you and say, "Does this look ok?" Well, I don't know; what's it supposed to look like? I don't know what should be on there; they should be providing for information about the IEP and our rights.*

*IEP is a big one. How frustrating IEP's can be if you have never been through the process. My son is in his 11th year of school. We still struggle with IEP's. We don't know how they work or what is available to us. What can we put in an IEP? We don't know. More education is needed for parents on how to set up an IEP.*

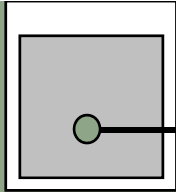
*An IEP, once signed, is a legal document, That is something I was not aware of. You don't know that up front.*

*They kind of develop IEP's to fit their staffing needs. They don't tell you that.*

*Isolated*

*With a typical child there are many opportunities for parents to volunteer and get involved with other parents and school functions. But that is just not there for special education parents.*

*Why do we not know each other?*



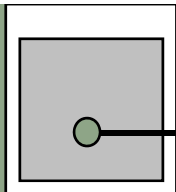
## 5) Education Heroes

:: The gifts of caring, acceptance, advocating, protection, inclusion... do not go unnoticed. Everyone has the opportunity to become a hero. The student, the administration, the teacher, the support staff, the parents, the other students, the school officer...

Focus on potential to be happy & successful

New teachers are more highly trained





## 5) Education Heroes

***“I am most concerned with the personal relationships between my son and everyone who has contact with him. I really don’t care what’s on the paper as long as it is nothing so egregious. The institutional categorization of my child is not as important as the people who advocate for my child. It is the personal relationships that carry weight with me.”***

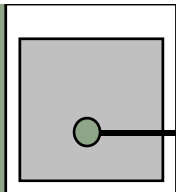
### **Special Education Teacher Heroes**

*We’ve had two behavior assessments in this district and they’ve both been really good experiences: meetings like this. Then comes this huge document describing what the challenges are and how we’re going to address them. And then there was the constant monitoring, down to every 10 minutes. So in addition to teaching 10 special needs kiddos, this teacher is documenting something from my kid. It’s just unbelievable. Then all of that was documented and reviewed in another meeting. The outcome of it was good but the continual paper work required of the teacher for the IEP seems like a mountain of trees. It’s a lot of work for the teachers.*

*My daughter just changed from junior high to high school, and high school is pretty scary, for both of us. But her teacher has made the transition easy for her, and so far she’s doing really well. I keep my fingers crossed.*

### **Para Hero**

*Our son has had the same Para for two years, and one day he came home with a book that had five word sentences, and he read the whole book to us. We were amazed. We never thought he would be able to do that. His Para loves what she does; she loves the kids. and every time we see her, he beams, she beams, we beam. She really cares.*



## 5) Education Heroes

### Other ‘Gatekeeper’ Heroes

*There’s a lot of gatekeepers in our kid’s lives. They coordinate and support the care for your child. The best (gatekeepers) are the ones who put our child’s picture on their wall, because they want to keep thinking about him or her, so they can identify things your child might need.*

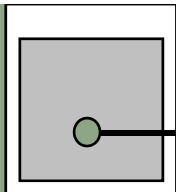
### Child Hero

*I remember talking with his teachers early on about all the testing they do, and they were telling me he scored in the 1% on this and that. I have pretty thick skin, so I can handle it; but I remember saying to his teacher, “Yeah, but you did not tell them about his scores on the hugs test.” That kid can give hugs like it’s nobody’s business, but nobody grades that, nobody scores that.*

### Parent Heroes

*Our son has been in three different school districts over the years, and the whole way along my wife and I have always had to advocate for him; whether it be going from one grade to another, one school to another, one teacher to another, we always have to be the ones who take charge and make sure our special needs son is getting what he needs. If you (as a parent) don’t do that, these kids will slip through.*

*We are caring, we care about our kids. We are their support, we are their advocate. And that is probably our main job as a parent of a kid with special needs.*



## 5) Education Heroes (continued)

### Security Officer Hero

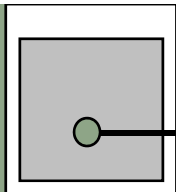
*One day in school some kid wanted to beat up my boy because he was in the Developmental Cognitive Disability classroom. So this kid follows (my son) around school. My son was on an errand and was followed in a room by this kid, and my son came out crying. I guess the Officer had seen him crying and went to talk to my son. The next day the bully kid came and apologized to my son. A little justice happened there.*

### Principal Hero

*They changed the security procedures at my child's pre-school after Newtown, Connecticut shooting. We could no longer go in the back door and find his Para; everyone had to enter through the front door and sign in. So the first day the principal saw us and walked us back to his class room, but the next day I went in the front door as required but I was not allowed to walk back into the school with him. So I was looking for his Para, hoping to see her so she could take my son back to the class. But the principal was there and noticed us, and he said, "Hey Wyatt, how's it going?" And he grabs his hand and walks him all the way back to his room. He didn't need to do that, but he did. He's the principal; he's got a million things to do. But he did that for my son. It was real nice.*

### School District Hero

*Moving from Arizona to (Minnesota) in the middle of our son's kindergarten year was such a night and day experience. In Arizona we felt like we had to fight so hard for everything, and we felt like we were not advocating for the right things for our child, the school system knew best. So we were constantly in a position where we were second guessing ourselves. When we moved to (Minnesota school district) my husband and I were blown away by our first IEP, because we were all ready to go tooth and nail, and the answers were, "Well of course we'll do that. And how about we add another five hours for this therapy per week. Do you want more?" I'm getting goose bumps just thinking about it because it was such a night and day experience.*



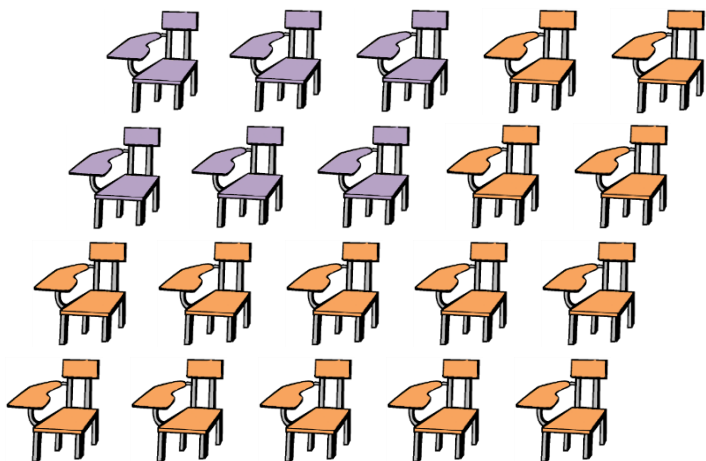
## 6) Integration to Inclusion

A lot of positive experiences of integration and inclusion were described by parents from all districts. The one common requirement for inclusion appears to be involvement from the entire school, including the principal, administrative staff, general education teachers, supporting staff, and students.

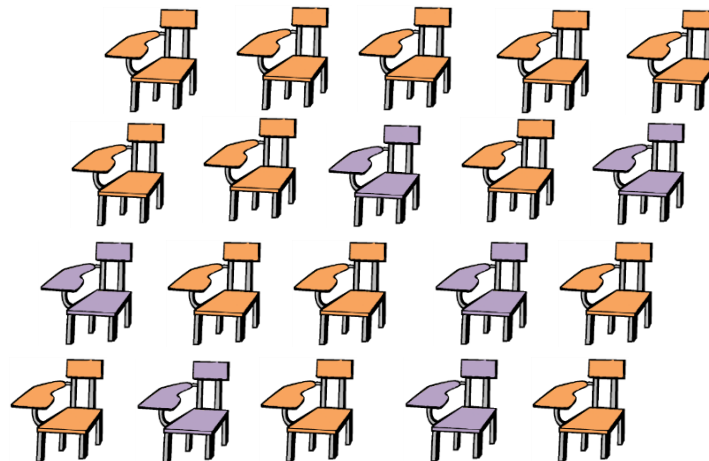
### Integration



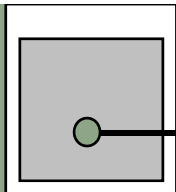
### Inclusion



- Traditional
- Back of the class
- "Allowed" to take class
- Didn't earn way through high school
- Inconvenience to regular class
- Interfering with regular class



- Classmates helped her feel included in school
- Gotten better
- included more this year
- Classmates give her positive encouragement
- If taught and given opportunity, he can do well



## 6) Integration → Inclusion

***“After we moved here it was the first time in five years that he wanted to go to school. He feels valuable here. He never has felt valuable before.”***

### **Transmitters of Good Energy**

*On a recent day when I brought my son to school, it had been a kind of grumpy morning at home, but when we got to school, everybody on the staff was out greeting the students, helping get kids off the bus. Everybody was smiling and happy. It's such a good environment and a happy place and everyone is there for the kids. I feel very fortunate that we were able to find this place and our son has really prospered there. Everyone there, the teachers and the staff, are like transmitters of good energy. I walked away feeling like, “I'm going to have a good day.”*

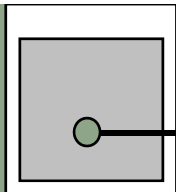
### **Accepting Classmates**

*Everyone knows Adam, they know he's sensitive and cries a lot. But the other kids know him and most of them are really nice about it, they know he cries and has problems with that, but nobody really cares, “Oh that's just Adam.”*

*Overall we've had an incredibly good experience with our son in school. All of his teachers and staff have been wonderful; his classmates take care of him and they are buddies with him.*

*I think it is important for teachers to get an introductory letter with each child with disabilities, so the teacher can know --from the parent-- exactly what is going on with the child. The teacher should tell the other children, “Her brain works differently...” It makes it so much easier with the other students. The kids rallied around her. The children were more thoughtful; they were protective of her. It should be almost mandatory for mainstream teachers to explain to the other children what is going on with these kids with disabilities kids.*





## 6) Integration → Inclusion

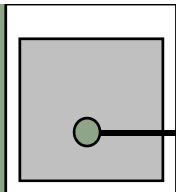
### Collaboration

*It is a very collaborative working environment now. The nice thing is that teachers have been flexible, things have changed! Until you are communicating openly it is just a lot of butting heads, and when you finally realize you are on the same page, it is open communication and you are all working together. It is a collaborative effort between parents and teachers, which makes it very nice.*

### Progress: From a Chevy to a Cadillac

*From my son's preschool I asked if I could have more daily communication from his teacher, and (in a hallway conversation) she ended up yelling at me, and then she started crying. I ended up consoling her. We ended up moving to a different district, and the first day I got a photo of my son in my inbox showing his first day at school. He was celebrated and loved for what he was able to accomplish that day, rather than being described as stubborn or unwilling to do some activity. There was such a difference between the two systems; I think the (first) district teachers had very little training on kids with disabilities, and (the districts) had completely different philosophical frameworks. The director of (the first district) told me, "We are not the Cadillac, we're the Chevy."*

*This year my son transitioned from preschool to a new school for kindergarten, and he's doing so much better. They have a program for students with autism and the entire faculty is great. The special ed. teachers, the general ed. teachers, the staff, the principal, everyone is truly concerned, and they always get back to me if I have questions or concerns. I still have to advocate for my son, because I know things they don't know about him, but they listen to me.*

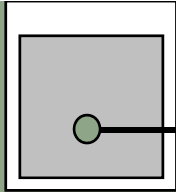


## 6) Integration → Inclusion

### **Progress: From a Chevy to a Cadillac** (continued)

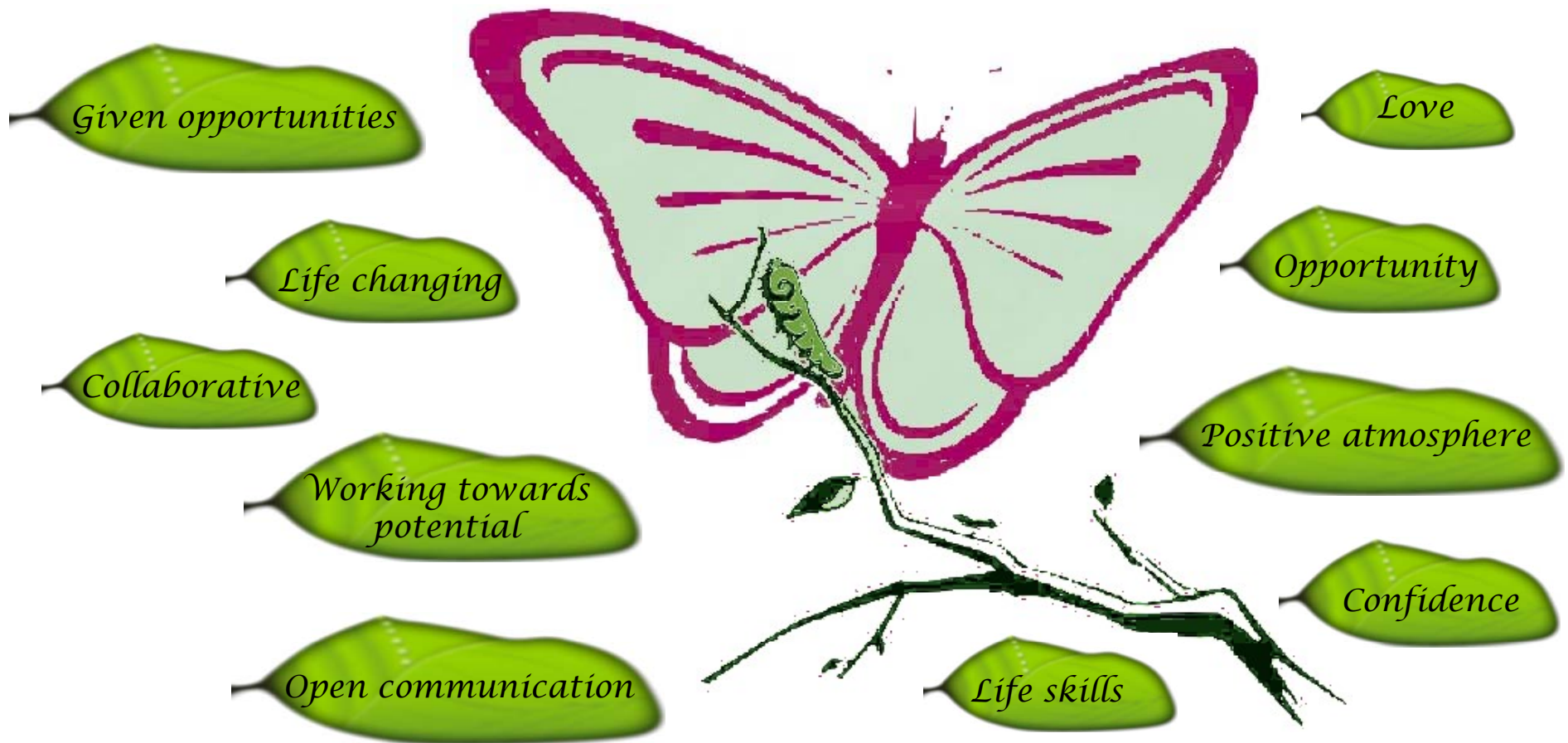
*I agree with everybody who says that younger teachers are a little more including and open to the idea of inclusion. In (our district's) public school system, our kids are given the chance to get as much out of the wider world that they can handle.*

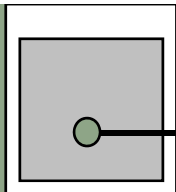
*My son has Down Syndrome and is in the third grade. In 2<sup>nd</sup> grade he got a brand new (general education) teacher. She has taken full ownership of him and his education. He is fully included for the main things like math and reading. If he would have gone to special ed. classes for math and reading there is no way he would be doing what he is doing today. Their expectations are so dated with Down Syndrome, from what I have found, really low. Inclusion is so important with him because that's how he gets exposed to stuff, and he can handle it.*



## 7) Transformation

:: Learning leads to transformation; it's the goal of education. The ultimate goal of public education is transformation to productive and fulfilling adulthood. But for students with developmental disabilities, transformation of this type is far from guaranteed.





## 7) Transformation

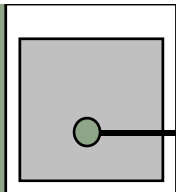
***“I think of all the phone calls I have logged, and I think of all the frustrations he has had, and I think there is this little spirit inside him that didn’t get beaten down. I don’t know how he made it, but he now feels like he can be a contributing member of his class.”***

### Underestimated Capabilities

*We’ve had amazingly good experiences over the years in the public schools with our son with autism. But now our son is in high school and I had a chance to meet his living skills teacher, who was a very nice man. I wanted to learn more about his living skills class, and he started talking about preparation for employment, and we were having this lovely friendly conversation, and all of a sudden I realized that what we were talking about was having my son, who’s brilliant with computers, shadow people doing jobs at McDonalds; not that there’s anything wrong with working there, but he was talking about our son, who is very smart and able, being given an opportunity to learn how to fold napkins. The conversation just stopped then.*

### Missed Opportunities

*All of a sudden last May I got an email from someone I’ve never met saying our son is going to have to change schools (next year) because they’re closing the program. What makes me very sad about this is that the school district doesn’t look at what the children with disabilities give to the including students and the whole school environment; it’s way more than what they can give to my child. And I’ll tell you, my child will give more to this world than a lot of college graduates will. I think that as an education system, we ignore those intangible valuable things that our kids can give to society. Instead, we house them in a place that’s geographically and financially convenient for the district.*



## 7) Transformation

***“I think of all the phone calls I have logged, and I think of all the frustrations he has had, and I think there is this little spirit inside him that didn’t get beaten down. I don’t know how he made it, but he now feels like he can be a contributing member of his class.”***

### **Misunderstood**

*With all the support my son has had over the years, since he was diagnosed in third grade -- support from a great district, family, friends, neighbors; I’m leaving the system thinking: It shouldn’t have been this hard. It’s been really, really difficult to get him through school. He’s 18 now, has Asperger’s; and if he came in here now you’d think he’s a really great kid; but I feel like the system could never quite figure him out, or the path he should go on.*

### **I Have Dreams**

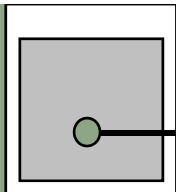
Moderator: *“What are you thinking after graduation?”*

Student 1: *“Going to college to be a neonatal doctor for premature babies. Or cleaning.”*

Student 2: *“I want to be a cop in Las Vegas, or work in a pet shop.”*

### **Blossom**

Case manager: *“..a student I helped get a job, he was having a difficult time had no job experience, had never volunteered, has a bad reputation in the area. He had been working with me for about seven weeks the last hour of the day, cleaning up some things. He eventually found a job, is being very successful, based on me giving him a reference, calling his workplace, helping him to get that door open. He has been there for four months and he is still working, seeming to blossom. And he is not getting in to as much trouble at school. So that is a big plus.*



## 7) Transformation (continued)

### **Breakthrough**

Special Education Teacher: *We had a girl in her early teens who was a screamer, and she was non-communicative; she could not talk. We finally were able to control her outbursts by rewarding her with a soft drink or other treat, when she maintained control for a period of time. One time I was in the break room with another teacher and this student. The other teacher had a tall glass of iced tea. The student was agitated; she was trying to tell us something but we couldn't figure out what it was. Finally she wrote some letters on a napkin, kind of scribbled and jumbled. I looked at it and realized, "Oh, she wants your iced tea!" We slid the glass over to her and she drank it all down. It was the 1<sup>st</sup> time she was able to successfully tell us what she wanted. We special education teachers live for those moments, and I wept.*

### **Exceeding Expectations**

*When they had him in the right situation, he learned to read; we never thought he'd do that. He learned to write; we never thought he'd do that.*

*Our son came home one day in fourth grade and told us they were putting on a school play and he was the narrator. He was going to stand up in front of everyone with a microphone and introduce each of the four plays the kids were putting on. He said he needed to tell some jokes too. He was not at all afraid, and it was great. And people were coming up to him afterwards saying what a great job he did and how good he was. He was a hit, he had a good time and he was beaming! He's usually a pretty quiet kid, but you give him a microphone and he changes.*

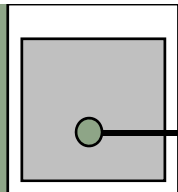
## **Contents:**

**1:: Introduction**

**2:: 7 story themes**

**3:: Future Back**





# Future Back -- introduction to the method

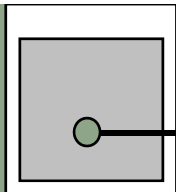
From the clusters of story elements that were constructed and defined by the parent respondents; an understanding of the current state of public education, as it applies to students with developmental disabilities, that represented their vantage point was established. Their similar experiences in this domain uncovered patterns of reoccurring outcomes. Such entrained cycles of behaviors and outcomes can be redefined into potential new narratives with the assistance from the Future Back exercise. Future Back helps identify key events, actions and perceptions, and how they have the potential to influence future events and outcomes in a positive or negative way.

## How it works:

- Step 1: As a group, the parent focus group/workshop participants were instructed to identify elements that would describe a best and worst future imaginable as it applies to public education services for students with developmental disabilities and their families. These elements were recorded on an easel pad by one of the moderators.
- Step 2: The group was then asked to identify a significant event or turning point that immediately preceded and helped shape this future scenario.
- Step 3: This process was then repeated, identifying significant events that preceded the one that was previously identified. The process continued, event by event. until the string of events found its way back to the current state.

The results from all Future Back exercises were matched up to one another. Commonalities of events and paths were uncovered. These common elements were then combined and organized into coherent paths that lead to the future outcomes. ***We think you will enjoy the next slides of future possibilities.....***

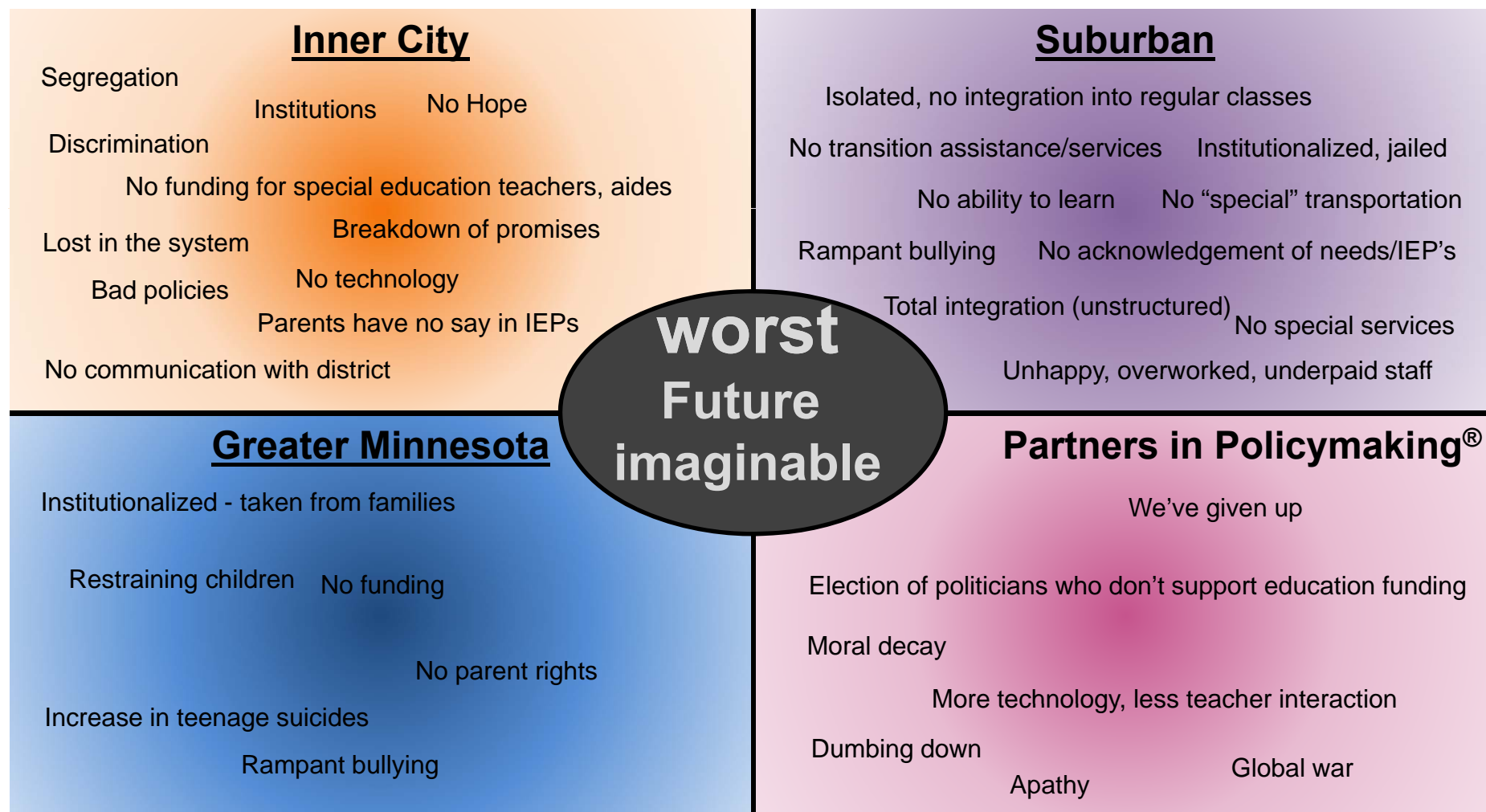


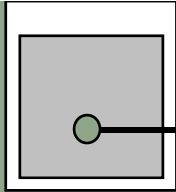


# Future Back -- worst future imaginable

:: Shown below are the words and phrases that were mentioned by each of the four focus group/workshops.

:: All four groups had similar mentions regarding 'funding.' Three of the four participant groups mentioned 'institutions.'





# Future Back

Colors distinguish which market each *turning point* came from:

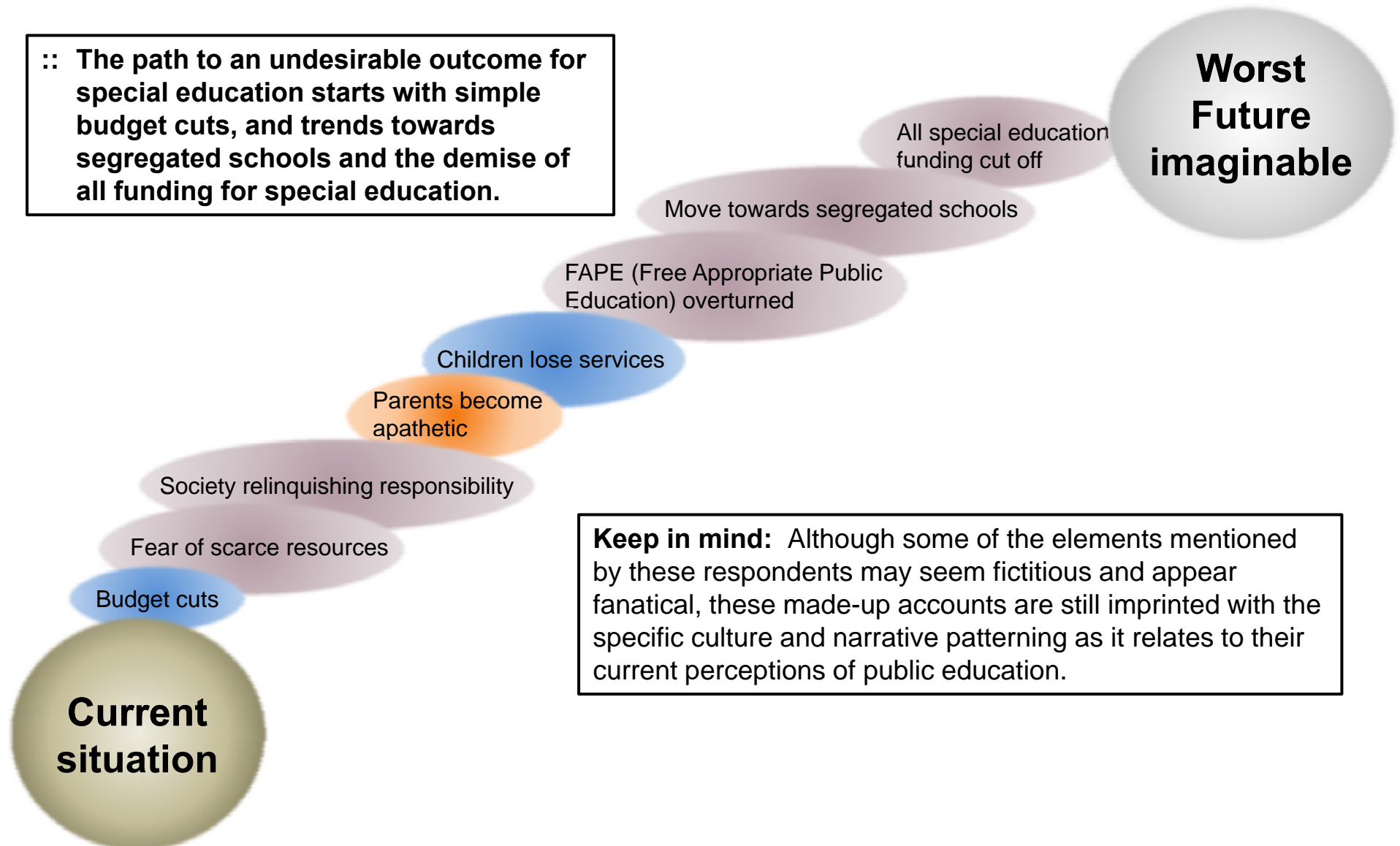
Inner city

Suburban

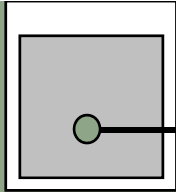
Greater Minnesota

Partners in Policymaking®

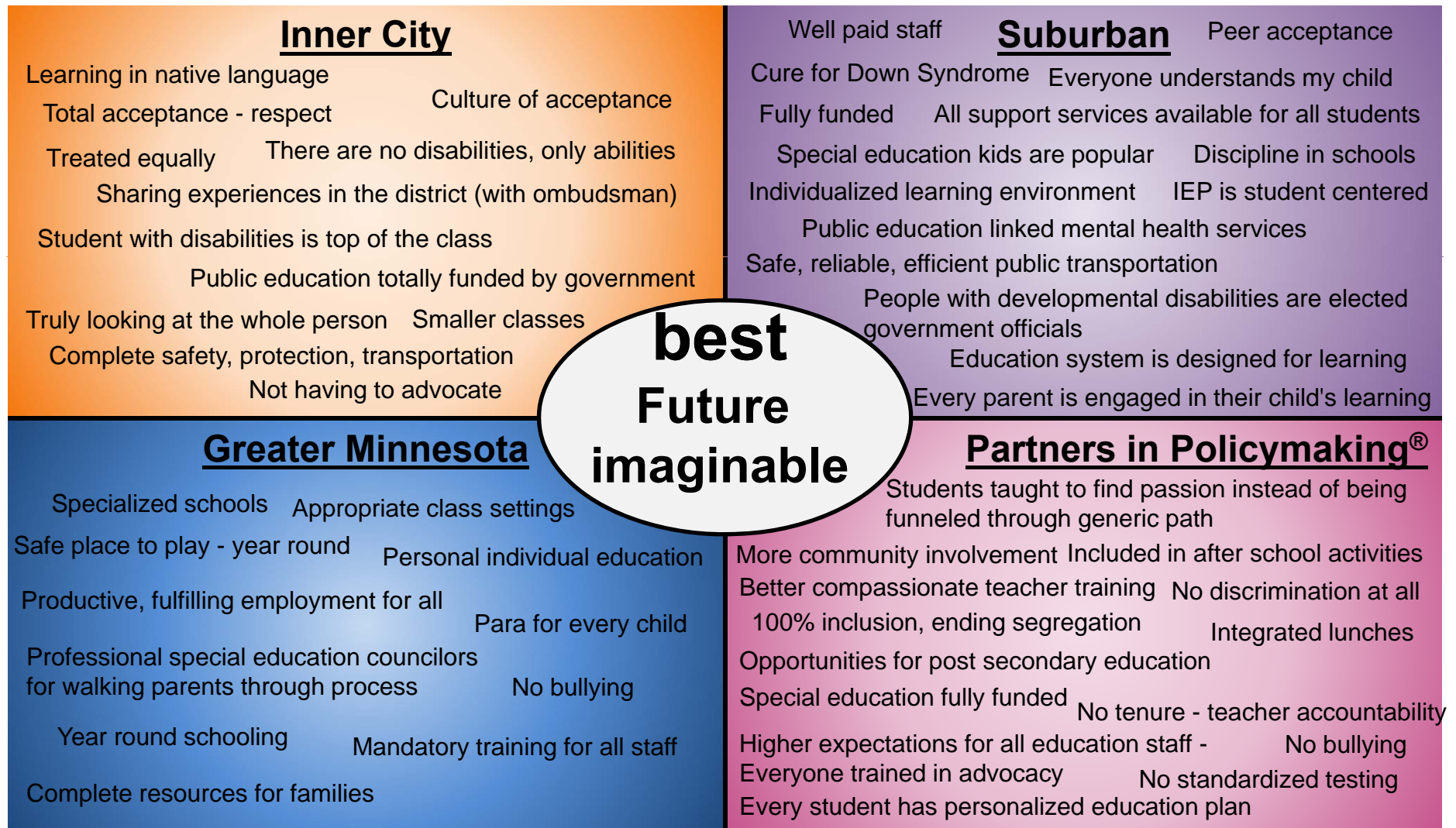
:: The path to an undesirable outcome for special education starts with simple budget cuts, and trends towards segregated schools and the demise of all funding for special education.

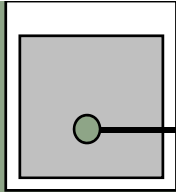


**Keep in mind:** Although some of the elements mentioned by these respondents may seem fictitious and appear fanatical, these made-up accounts are still imprinted with the specific culture and narrative patterning as it relates to their current perceptions of public education.



# Future Back -- best future imaginable





# Future Back

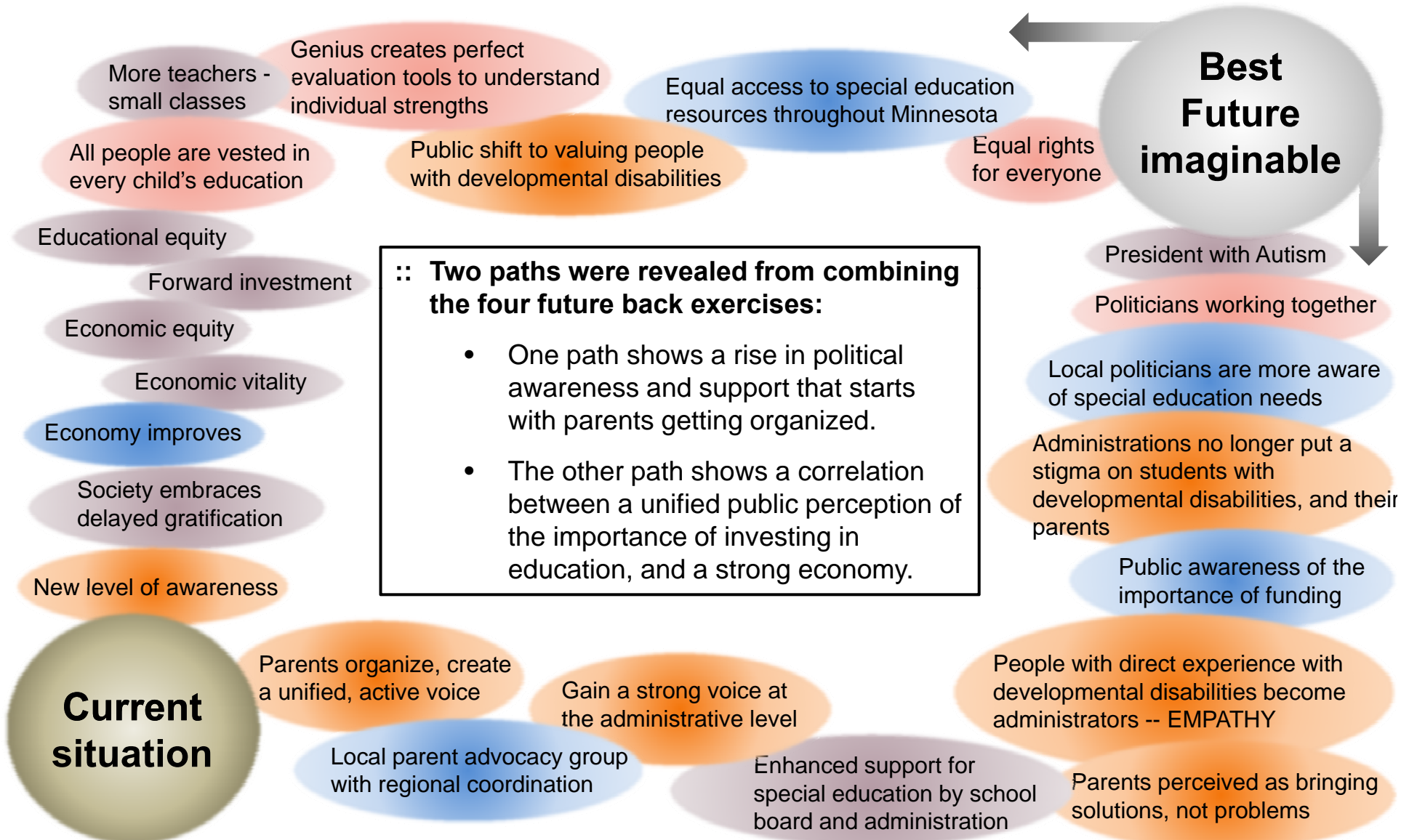
Colors distinguish which market each *turning point* came from:

Inner city

Suburban

Greater Minnesota

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Project #2210

April 16 2013

# Thank you....

**The Minnesota Governor's Council on  
Developmental Disabilities**

Promoting Independence, Productivity, Self-Determination, Integration and Inclusion

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