• Emily Levine
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• www.assew.org
Parent founded and parent led organization, reminding you that little people who have autism........
Turn into big people with autism
PARENT GOALS

Presume Competence
High Expectations
Access to general curriculum
Friends
Opportunities
Adulthood - Full and meaningful life in the community
PARENT GOALS

We want inclusion!
New to our district pioneers
lots of obstacles
SCHOOL GOALS (OUR PERSPECTIVE)

Services were deficit-driven
Expectations seen as unrealistic
High value placed on compliance and conformity
Opportunities conditional based on behavior
Focus on consequences, not causes
### At a glance — Outcomes of adults with ASD (18-64 years) who received DD services

<table>
<thead>
<tr>
<th>DD Service Access</th>
<th>Did not receive all needed services</th>
<th>Received respite services</th>
<th>Average number of services received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>25%</td>
<td>51%</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Reportedly did not receive all the services they felt they needed.</td>
<td>Received respite care if they lived in the home of a parent or relative.</td>
<td>Was the average number of services funded by state or county agencies from a list of 13.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health and Mental Health</th>
<th>Had co-occurring health conditions</th>
<th>Had co-occurring mental health conditions</th>
<th>Took medication to treat mental health conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>51%</td>
<td>54%</td>
<td>64%</td>
</tr>
<tr>
<td></td>
<td>Had at least one additional health condition from a list of 11 common conditions.</td>
<td>Had anxiety, mood disorder, psychotic disorder, or “other mental illness/psychiatric diagnosis” in addition to ASD.</td>
<td>Took medication for either mood disorders, anxiety, and/or psychotic disorder, and/or behavioral challenges.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment and Other Day Activities</th>
<th>Had a paid job in the community</th>
<th>Were in unpaid, activities in facilities</th>
<th>Had no work or activity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14%</td>
<td>42%</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>Worked in the community for pay in settings that also employed people without disabilities.</td>
<td>Participated in unpaid activities in facilities with others with disabilities (sometimes called day programs).</td>
<td>Had no work or activities in the previous two weeks in community or facility-based settings.</td>
</tr>
</tbody>
</table>

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To Your Health

People on the autism spectrum live an average of 18 fewer years than everyone else, study finds

By Ariana Eunjung Cha
Washington Post, March 18, 2016
Premature death in autistic adults isn't due to diseases, such as heart ailments or cancer, that are the main killers in the general population.

It's suicide.

Premature mortality in autism spectrum disorder
Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte
The British Journal of Psychiatry Mar 2016, 208 (3) 232-238; DOI: 10.1192/bjp.bp.114.160192
"We don't understand why adults with autism have higher rates of depression and suicide," said Lisa Croen, PhD, director of the autism research program at Kaiser Permanente Northern California. "More research is needed to understand the basis for these findings: Is it genetic predisposition? Social isolation? Complications from medications?"

https://iancommunity.org/diagnosing-depression-autism
Students who struggle with Autism and.....
Common co-occurring conditions
Anxiety
Depression
ADHD, OCD
Learning challenges
Seizure disorders
Anxiety

Things must go perfectly, so I must plan endlessly.

Nothing will ever go perfectly, so don’t even try.

I have to try harder.

from Raging Nerd
Depression

- I’m exhausted and it’s not worth the effort
- I don’t have the energy for 1 thing, let alone 8000 things

Anxiety

- Things must go perfectly, so I must plan endlessly
- I have to try harder

Nothing will ever go perfectly, so don’t even try

from Raging Nerd
ANXIETY

Things must go perfectly, so I must plan endlessly.

I have to try harder.

Depression

I’m exhausted and it’s not worth the effort.

Nothing will ever go perfectly, so don’t even try.

I don’t have the energy for 1 thing, let alone 8000 things.

Hey, what’s that shiny thing x 8,000.

ADHD

I have to try harder.

F**K!!

from Raging Nerd
OTHER FACTORS AFFECTING STUDENT

- Sensory overload
- Bullying
- Exhaustion and stress
- Rejections by staff and peers
FACTORS AFFECTING COMMUNITY

STIGMA
Fear of meltdowns
lack of understanding of triggers
Societal bias against people with differences
Exercise
WHY????

Why are you being such a Debbie Downer?
Lack of Acceptance

the Specter at the feast
need for role models and hope
our experience never reflected
SNAPSHOT NOT PREDICTION

We can do better
Preaching to the choir
we are here to do the work
Changing hearts and minds one at a time
BUILDING ACCEPTANCE

Proximity does not equal inclusion
“buddy” pairing needs to be interest-based
Model appreciation of out-of-the-box thinking and insights
“When we’re playing games, we’re not suffering.”

Jane McGonigle

REALITY IS BROKEN
Why Games Make Us Better and How They Can Change the World

NEW YORK TIMES BESTSELLER

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Southeastern Wisconsin
IT IS OK TO BE YOU
Be sure your goal is not cure
Students internalize typical with success
Can lead to self-loathing
Anger at not being accepted, lack of agency
Bloom where you are planted.
Donna Williams

to love is to empower, to care is to care enough to help in a way that empowers and never puts the person into baby mode. Even if they are scared, terrified, to acknowledge that, be kind to that, but empower them to remember how whole and strong and resilient and resourceful and capable of endurance and acceptance that they ALSO are. To fail in doing this is to rob them of this essential part of their own journey.
SHARE THE LOAD

Meet us half-way
Nurture strengths and interests
Identify strengths and interests if they aren’t apparent
Don’t make acceptance conditional on acting NT
REDUCE STIGMA

Talk about disability
Secrets breed shame
Model repairing mistakes
Teach good citizenship
I am beautiful, not broken.
Different, not less.
Challenged, not challenging.
Overwhelmed, not spoiled.

walk down autism lane
Autism is not a choice,
ACCEPTANCE is.

-author unknown
QUESTIONS?