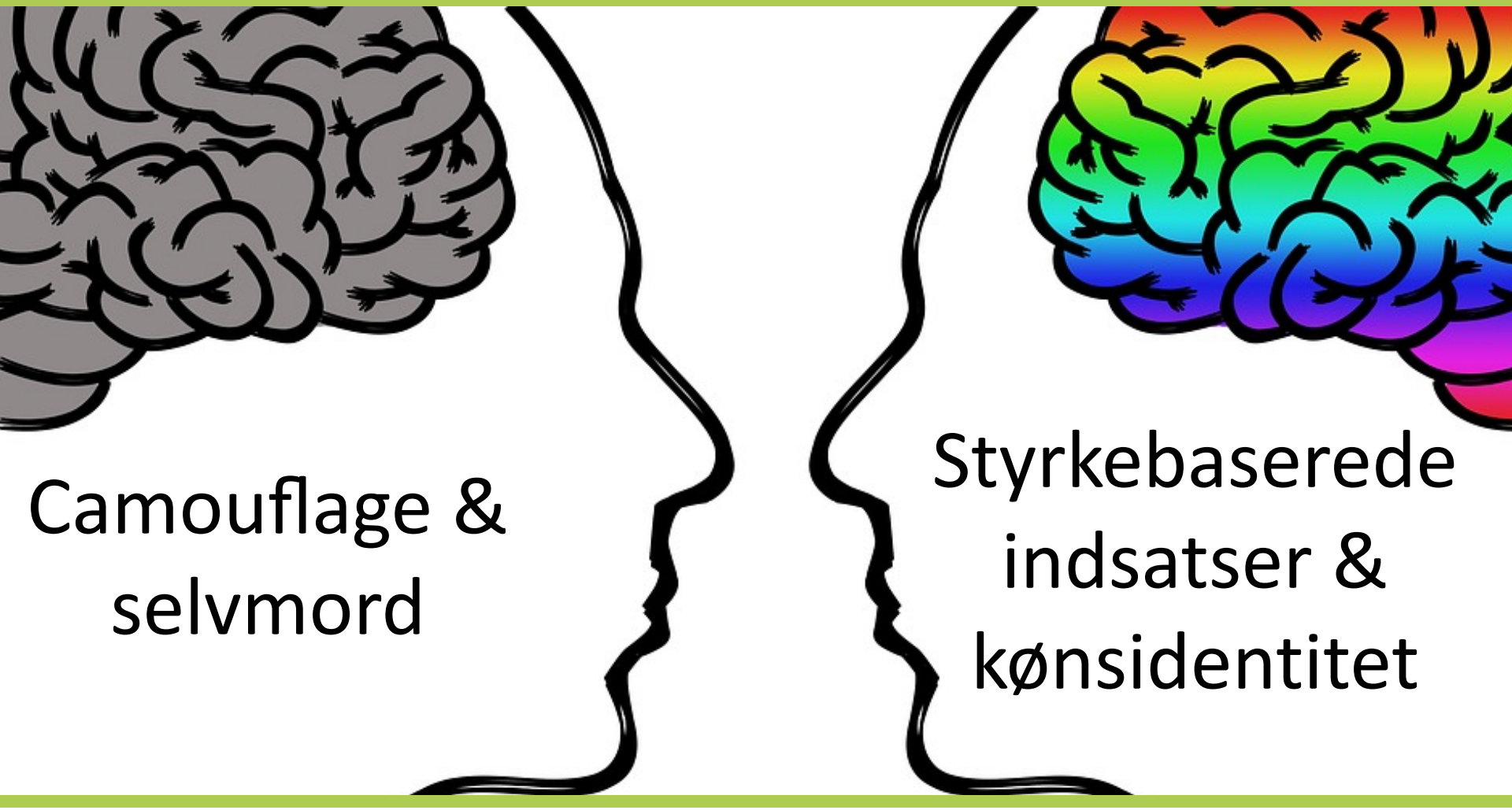
Handout: Udvalgte tendenser fra international autismeforskning



Camouflage

”I camouflage by putting on a character… I treat my clothes rather like costumes, and certain items of clothing help me to uphold certain personality characteristics of which character I am on that occassion. I have a repertoire of roles for: cafe work, bar work, uni, various groups of friends, etc. They are all me at the core, but they are edited versions of me, designed to not stand out for the `wrong´ reasons”

(Kvinde, 22 år i Hull et al., 2017 s. 2526)

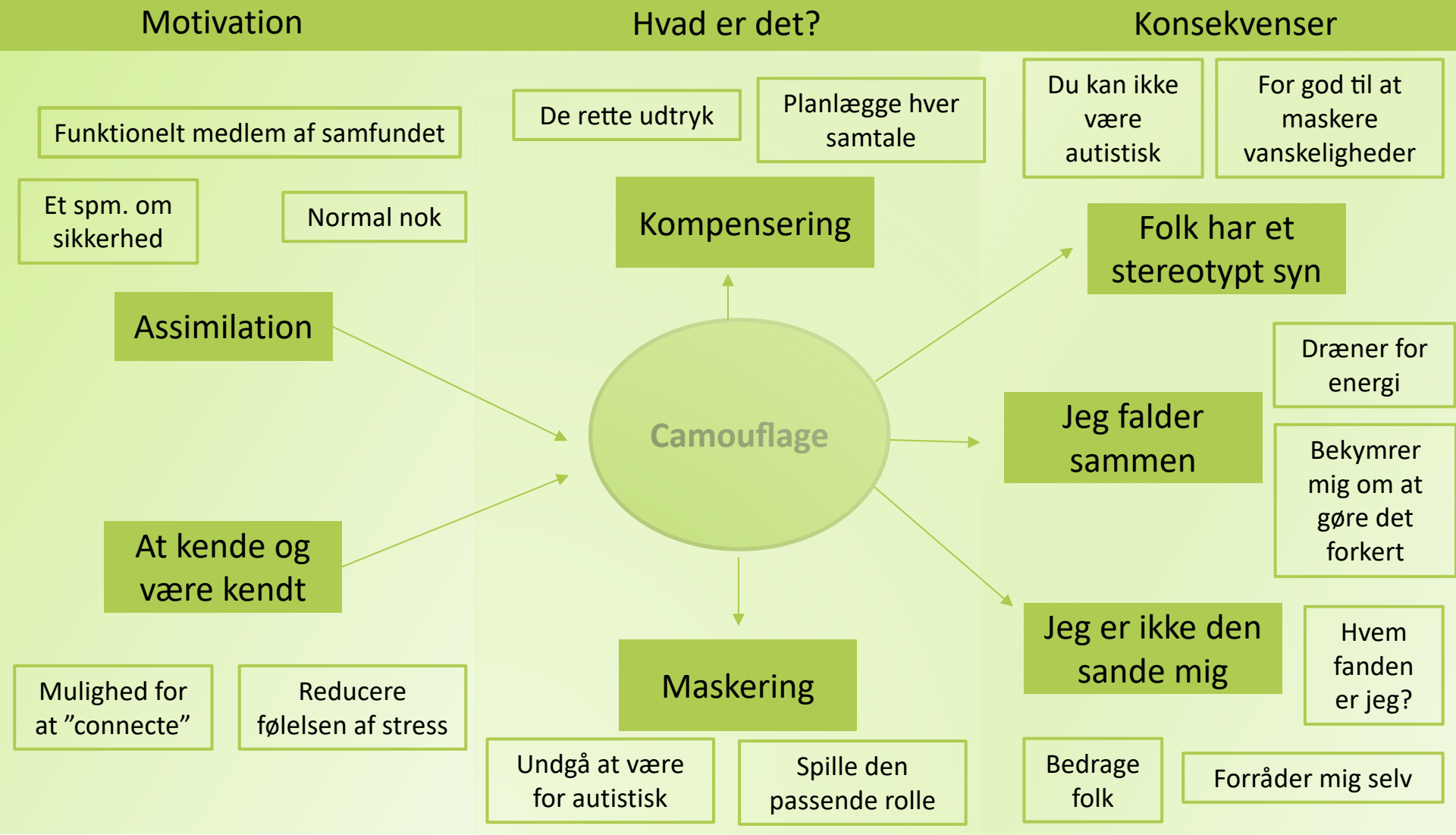
”I try to copy socially succesful people by trying to imitate their speech and body language and trying to understand their interests.”

(Mand, 71 år i Hull et al., 2017 s. 2526)

Camouflage

- Adfærd som kompenserer eller maskerer autistiske karakteristika under sociale interaktioner (Hull et al., 2017)
- Udbredt fænomen blandt autistiske mennesker
- Piger og kvinder ser ud til at camouflere mere (Lai et al., 2017; Ratto et al., 2017)
  - Bedre til at få venner, men ikke fastholde (Hiller et al., 2014)
  - Autistiske piger i skolegården sværere at spotte (Dean et al. 2016)
  - Piger bruger gestik mere levende (Rynkiewicz, 2016) og camouflerer sprogligt (Parrish-Morris, 2017)

Model: Camouflage proces



Kilde: Hull et al. 2017, Fig 1., s. 2524 (min oversættelse)

Godt eller skidt?

- I Hull et al. (2017) studie oplevede langt størstedelen ubehagelige eller uønskede konsekvenser af at camouflere, nogle oplevede en tilfredsstillelse:

" Individuals who are better able to camouflage their ASC characteristics might feel more able to make friends, improve their social support, and perform better in job interviews."

- Hull et al. 2017, 2521, min oversættelse

" Where camouflaging is unsuccessful, strenuous, or if the person feels forced to camouflage, it may be associated with high stress level, low mood and low self-esteem. In addition, the pressure to maintain successful camouflaging may lead to anxiety for individuals with ASC."

-Hull et al. 2017, 2521, min oversættelse

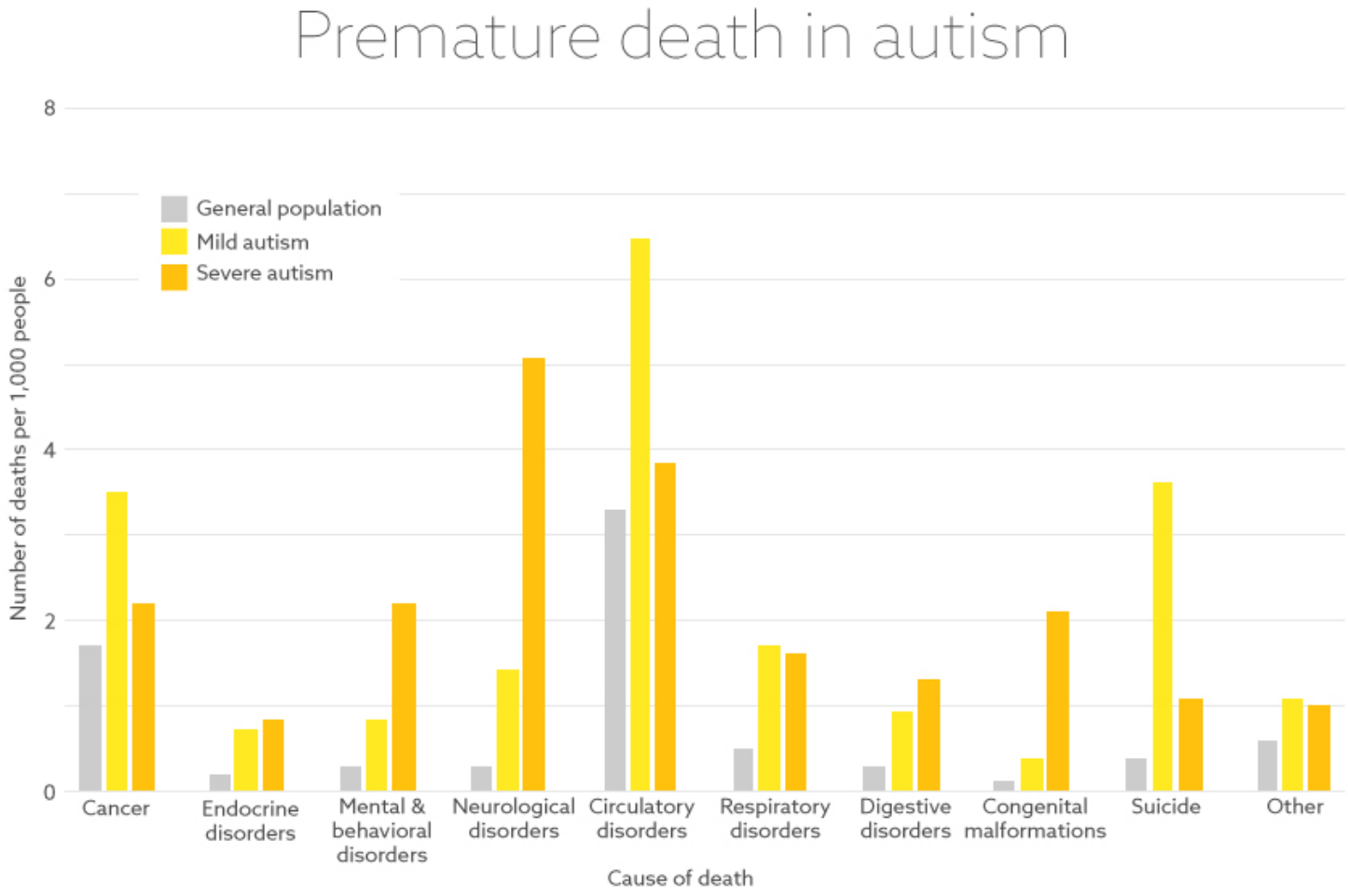
- Camouflage er associeret med depression (Cage et al. 2018; Lai et al., 2017)

Spørgeskema camouflage

- **Uddrag:**
  - I hvilke situationer camouflerer du?
  - Hvor ofte camouflerer du i sociale situationer?
  - Hvor ofte har du:
    - Forsøgt at skjule vanskeligheder med øjenkontakt ved at lade som om du giver øjenkontakt?
    - Forsøgt at gøre dine bevægelser mere naturlige ved bevidst at øve dem alene?
    - Øvet ansigtsudtryk foran spejlet når du er alene?
    - Studeret menneskers adfærd i film ved at bestemte klip igen og igen og forsøgt at imitere disse?
    - Forsøgt at lave regler for at guide dig i social interaktion?
  - Hvad er de positive / negative konsekvenser af at camouflere for dig?

Kilde: Hull et al. 2017, appendix 1 (min oversættelse og uddrag)

Tidligere død (selvmord)



Kilde data: Hirvikoski et al., 2016

Kilde illustration: Nigel Hawtin: https://www.spectrumnews.org/news/large-swedish-study-ties-autism-to-early-death/

Selvmord

- Autistiske mennesker er i højere risiko for Selvmordstanker, selvmordsplaner, selvmordsforsøg og selvmord, men resultaterne varierer meget (Hirvikoski et al., 2018; Cassidy et al., 2018; Chen et al., 2017: Culpin et al., 2018; Richa et al., 2014; Jackson et al., 2018; Hedley et al, 2018)
  - Selvmordstanker: 66 %. Selvmordsplaner eller forsøg: 35 %. Signifikant højere forekomst end generel befolkning, mennesker med en eller flere medicinske sygdomme eller mennesker med psykotiske lidelser (Cassidy et al., 2014)
  - 5 gange større risiko for selvmordsforsøg: 1/56 mod 2/313 (Croen et al., 2015)
  - Merkant større risiko for at dø af selvmord (Hirvikoski et al., 2016) – størst for for kvinder uden MR. Selv efter kontrol for depression og ADHD er der større risiko for selvmordsforsøg og selvmord (Hirvikoski et al., 2018 INSAR).
  - Review studie med 13 studier: Selvmordstanker: 11-66 %. Selvmordsforsøg 1-35 %. (Hedley & Uljarevic, 2018)

Kendte risikofaktorer

- Kendte risikofaktorer:
  - Mobning
  - Depression og social isolation
    - Dobbelt så høj risiko for depression og 8 gange større risiko for bipolar lidelse (Croen et al., 2015)
    - Selvrapportering: Depression: 32 % i samme population: Selvmordstanker: 66 %. Selvmordsplaner eller forsøg: 35 %, (Cassidy et al., 2014)
    - Symptomer på depression kan måske manifestere sig anderledes hos autister og kan derfor måske overses (Uljarevic et al., 2017)
  - Arbejdsløshed
  - Snævert socialt netværk
  - Selvskade
  - Ændringer ift. søvn, appetit og sociale relationer

Autisme som selvstændig risikofaktor

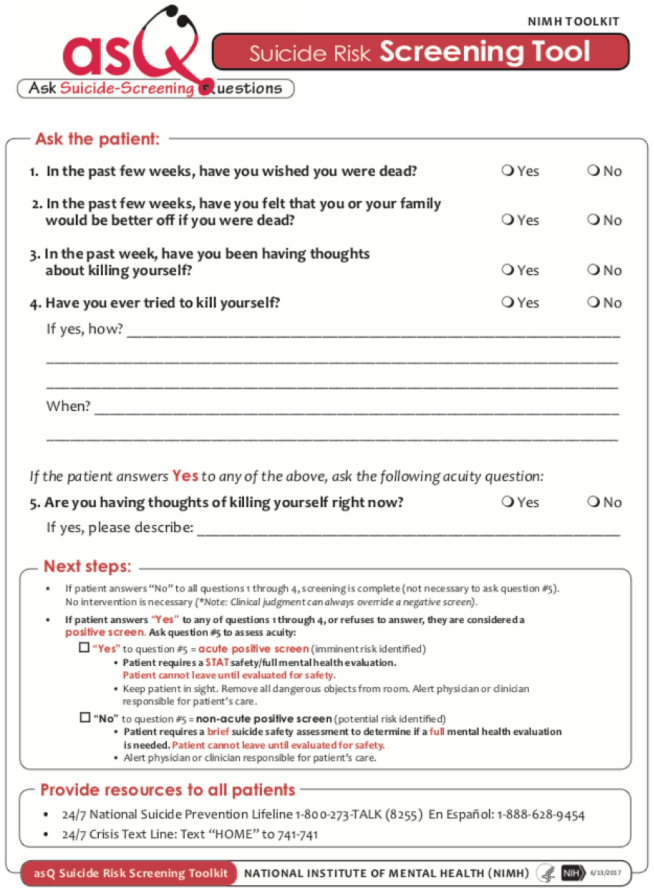
”ASD er en selvstændig risikofaktor ift. selvmordsforsøg (..) uafhængig af forekomsten af (..) depression, bipolar lidelse og alkohol og stofmisbrug”
(Chen et al., 2017, min oversættelse)

- Vanskeligheder ved at opsøge og modtage hjælp – manglende tillid til at hjælpen hjælper
- Misforståelse om at autistiske mennesker ikke har komplekst og rigt følelsesliv
- Konsekvenser af camouflage
- Autisme får skylden for mistrivsel
- Stigmatisering og manglende accept fra samfundet

- Når autistiske mennesker har forsøgt selvmord, er det mindre sandsynligt, at de bliver tilknyttet støtte (Kato et al., 2013)

Start med at spørge?

- ASQ (Ask Suicide-Screening Questions)
- Studie i ASD population (> 8 år) (Rybczynski et al., præsenteret på INSAR Annual Meeting 2018):
  - 317 fik tilbuddet. 1 ud af 3 afslog at deltage
  - 13.7 % screenede positivt mod ca. 5 % i grupper af andre psykiske tilstande
- Studie i ASD population (Vasa et al., 2017)
  - 104 børn og unge på psykiatrisk skadestue
  - Ca. 30 % screenede positivt, heraf blev 65 % opdaget via ASQ



NIMH TOOLKIT

asQ Suicide Risk Screening Tool

Ask Suicide-Screening Questions

Ask the patient:

1. In the past few weeks, have you wished you were dead? ❍ Yes ❍ No
2. In the past few weeks, have you felt that you or your family would be better off if you were dead? ❍ Yes ❍ No
3. In the past week, have you been having thoughts about killing yourself? ❍ Yes ❍ No
4. Have you ever tried to kill yourself? ❍ Yes ❍ No

If yes, how? _____

When? _____

*If the patient answers **Yes** to any of the above, ask the following acuity question:*

5. Are you having thoughts of killing yourself right now? ❍ Yes ❍ No

If yes, please describe: _____

Next steps:

- If patient answers "No" to all questions 1 through 4, screening is complete (not necessary to ask question #5). No intervention is necessary (*Note: Clinical judgment can always override a negative screen).
- **If patient answers "Yes" to any of questions 1 through 4, or refuses to answer, they are considered a positive screen. Ask question #5 to assess acuity:**
  - ☐ "Yes" to question #5 = **acute positive screen** (imminent risk identified)
    - **Patient requires a STAT safety/full mental health evaluation. Patient cannot leave until evaluated for safety.**
    - Keep patient in sight. Remove all dangerous objects from room. Alert physician or clinician responsible for patient's care.
  - ☐ "No" to question #5 = **non-acute positive screen** (potential risk identified)
    - **Patient requires a brief suicide safety assessment to determine if a full mental health evaluation is needed. Patient cannot leave until evaluated for safety.**
    - Alert physician or clinician responsible for patient's care.

Provide resources to all patients

- 24/7 National Suicide Prevention Lifeline 1-800-273-TALK (8255) En Español: 1-888-628-9454
- 24/7 Crisis Text Line: Text "HOME" to 741-741

asQ Suicide Risk Screening Toolkit NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) NIH 4/13/2017

Spørgeskema tilgængeligt på: https://www.nimh.nih.gov/labs-at-nimh/asq-toolkit-materials/index.shtml

midt regionmidtjylland Specialområde AUTISME Hinnerup Kollegiet – Gudenåkollegiet – Bækkeskolen

Styrker og interesser

Evner ift. en særlig kognitiv stil
(Fx. Dawson et al., 2007)

Evner ift. særinteresser og disses potentiale ift. beskæftigelse
(Fx Kirchner & Dziobek, 2014)

Positive aspekter relateret til personlighed og karakter

→

Signaturstyrker:

- Åbensindet
- Autentisk
- Kærlighed til at lære
- Kreativitet
- Retfærdighed

(Kirchner et al., 2016)

Styrkebaserede indsatser: Coding Club

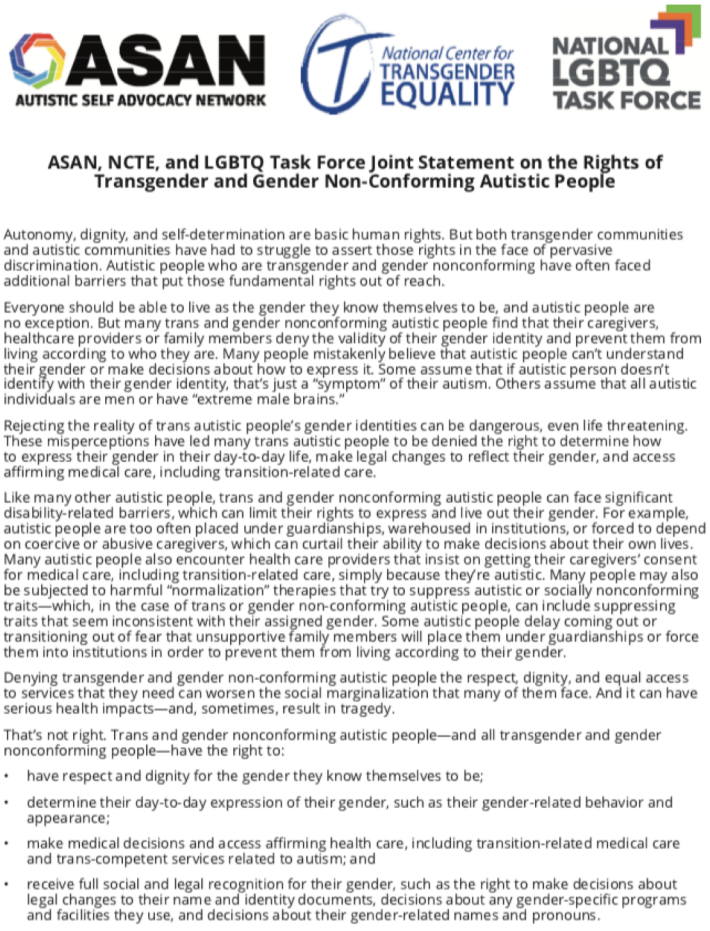
Facilitatorer	Aktiviteter	Miljø
• Delte interesser • Individuel og kollektiv tilgang • Eksperter • Autentiske • Flexible • Evne til at lære	• Inkorporere interesser • Visuelle komponenter • Valgmuligheder • Mål for udvikling af færdigheder • Mål for Karrier • Peer mentor	• Accept • Intet pres • Alle har autisme • Regler og grænser • Overfyldt og støj

Kilde: Jones et al., 2018, s. 26, mine uddrag, opsætning og oversættelse

Kønsidentitet

- Autistiske mennesker er overrepræsenterede i kønsdiverse grupper (transkønnede, non-binary mv.)
  - Mennesker henvist med kønsrelaterede udfordringer med en autismediagnose er overrepræsenterede: Prævalens på 6.3-13.3 % (Vries et al, 2010; Holt et al., 2016; Nahata et al., 2017; Shumer et al., 2016)
  - Der er øget forekomst af autistiske træk, når man screener mennesker henvist med kønsrelaterede udfordringer (van der Miesen et al., 2017)

Kønsidentitet



ASAN AUTISTIC SELF ADVOCACY NETWORK

National Center for TRANSGENDER EQUALITY

NATIONAL LGBTQ TASK FORCE

ASAN, NCTE, and LGBTQ Task Force Joint Statement on the Rights of Transgender and Gender Non-Conforming Autistic People

Autonomy, dignity, and self-determination are basic human rights. But both transgender communities and autistic communities have had to struggle to assert those rights in the face of pervasive discrimination. Autistic people who are transgender and gender nonconforming have often faced additional barriers that put those fundamental rights out of reach.

Everyone should be able to live as the gender they know themselves to be, and autistic people are no exception. But many trans and gender nonconforming autistic people find that their caregivers, healthcare providers or family members deny the validity of their gender identity and prevent them from living according to who they are. Many people mistakenly believe that autistic people can't understand their gender or make decisions about how to express it. Some assume that if autistic person doesn't identify with their gender identity, that's just a "symptom" of their autism. Others assume that all autistic individuals are men or have "extreme male brains."

Rejecting the reality of trans autistic people's gender identities can be dangerous, even life threatening. These misperceptions have led many trans autistic people to be denied the right to determine how to express their gender in their day-to-day life, make legal changes to reflect their gender, and access affirming medical care, including transition-related care.

Like many other autistic people, trans and gender nonconforming autistic people can face significant disability-related barriers, which can limit their rights to express and live out their gender. For example, autistic people are too often placed under guardianships, warehoused in institutions, or forced to depend on coercive or abusive caregivers, which can curtail their ability to make decisions about their own lives. Many autistic people also encounter health care providers that insist on getting their caregivers' consent for medical care, including transition-related care, simply because they're autistic. Many people may also be subjected to harmful "normalization" therapies that try to suppress autistic or socially nonconforming traits—which, in the case of trans or gender non-conforming autistic people, can include suppressing traits that seem inconsistent with their assigned gender. Some autistic people delay coming out or transitioning out of fear that unsupportive family members will place them under guardianships or force them into institutions in order to prevent them from living according to their gender.

Denying transgender and gender non-conforming autistic people the respect, dignity, and equal access to services that they need can worsen the social marginalization that many of them face. And it can have serious health impacts—and, sometimes, result in tragedy.

That's not right. Trans and gender nonconforming autistic people—and all transgender and gender nonconforming people—have the right to:

- have respect and dignity for the gender they know themselves to be;
- determine their day-to-day expression of their gender, such as their gender-related behavior and appearance;
- make medical decisions and access affirming health care, including transition-related medical care and trans-competent services related to autism; and
- receive full social and legal recognition for their gender, such as the right to make decisions about legal changes to their name and identity documents, decisions about any gender-specific programs and facilities they use, and decisions about their gender-related names and pronouns.

"Alle burde være i stand til at leve som det køn de selv ved de er og autistiske mennesker er ingen undtagelse (..). Mange mennesker tror fejlagtigt at autistiske mennesker ikke kan forstå deres eget køn eller træffe beslutninger om, hvordan de udtrykker det."

- ASAN, NCTE & LGBT Task Force, 2016, min oversættelse

Refleksioner ift. praksis

- Mindske behovet for camouflage: Opfattelsen i samfundet er betydningsfuld, vi bør arbejde aktivt for at reducere stigma fx ved fokus på styrker og nedbryde barrierer for autistisk deltagelse
- Vi skal behandle psykiatrisk komorbiditet
- Give plads til mentale åndehuller: Tid alene, blandt andre autistiske mennesker og / eller via styrkebaserede indsatser
- Kan vi give mere plads til samarbejdet omkring relationer og identitet (herunder kønsidentitet)?

Spørgsmål og kommentarer

fresir@rm.dk

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